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ABSTRACT

This document is a report to the Maryland State Planning Council on Developmental Disabilities which provides an assessment of the status and problems of older developmentally disabled and retarded citizens of Maryland. The executive summary describes the project background, basic needs identified by the project, developmental disabilities system and aging network services, a review of project activities, major findings and recommendations, and lists the advisory committee members. Chapter 1 discusses a 5-year plan of action and describes eight recommendations in detail. The second chapter defines the population and gives a profile of aging developmentally disabled persons, including discussions of developmental disabilities, aging, and demographics of the target population. Special service considerations and obstacles are discussed in the third chapter. Four shared and special needs (residential programs, day programs, health care, and advocacy) are discussed. The final chapter focuses on lessons learned about agencies, developmentally disabled and mentally retarded adults, families and caregivers, the maximizing of existing services, leisure and retirement, and the need for immediate education and training. Related references, planning and service activities of select Maryland agencies, and amendments to the 1987 Reauthorization of the Older Americans Act proposed by the Consortium for Citizens with Developmental Disabilities are appended. (ABL)

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Aging and Developmental Disabilities
Research and Planning

by

Thomas Ross, Ph.D.

and

Edward F. Anselio, Ph.D.

FINAL REPORT

to the Maryland State Planning Council
on Developmental Disabilities

April 1987

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THE AGING AND DEVELOPMENTAL DISABILITIES RESEARCH AND PLANNING PROJECT

by

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FINAL REPORT

TO THE MARYLAND STATE PLANNING COUNCIL

ON DEVELOPMENTAL DISABILITIES

April 1987

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Center on Aging

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AGING DEVELOPMENTAL DISABILITIES: RESEARCH AND PLANNING

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Preface

Developmentally disabled (DD) adults in Maryland are living longer in unprecedented numbers. Neither the DD nor the aging-related service system has had much experience dealing with the needs of large numbers of developmentally disabled elders; and the systems have had little experience dealing with each other. Maryland must have thoughtful planning and meaningful, cost-effective policies for these citizens. If left unattended, this impending problem may become a crisis. Further, as dollars for services generally become scarcer, it would be inadvisable to build parallel systems of services within DD and aging-related organizations. Cooperative planning must begin now.

This document represents eighteen months of effort by the project team at the University of Maryland Center on Aging, fifteen of which were spent in research and analysis and three in completing this Final Report. The Report contains eight major recommendations for action and 45 sub-recommendations. We trust that they will prove helpful in addressing the needs of this population of elders.

Acknowledgements

Our work was encouraged and supported by the Maryland State Planning Council on Developmental Disabilities. We are grateful for the Council's insight into an emerging area of concern -- the aging of the developmentally disabled -- and for their commitment to forward-thinking research and policy analysis. It is refreshing to probe a problem before it becomes a crisis.

We acknowledge the central contributions of our Baltimore and Montgomery Advisory Committees whose members are listed on pages 11 & 12 of the Executive Summary. Worthy of special thanks for their continuous help are the Developmental Disabilities Administration, particularly M. Doreen Croser and Iris Gordon, and the State Office on Aging, notably Rosalie Abrams, John Coe, Janice MacGregor, and (for singularly consistent support) Donna Folkemer.

Matthew Janicki of the New York State Office of Mental Retardation and Developmental Disabilities played a seminal role in helping us to formulate our research and coordinate our finings. Further, he and consultant Terry Perl of The Chimes, Inc., gave valuable advice in shaping the report.

Finally, we must recognize the extraordinary work of our colleagues at the University of Maryland Center on Aging: Florry Berkley and Nancy Evans who contributed their time to this project, Susan Nippes, Jo Welker and Ken Martin who persevered in good spirits through the initial research and countless revisions of the project's report.

EXECUTIVE SUMMARY

For 15 months (October 1985-December 1986) the multidisciplinary team associated with our project, **Aging and Developmental Disabilities: Research and Planning**, assessed the status and problems of older developmentally disabled and retarded citizens in Maryland. We were encouraged and supported in this work by the Maryland Developmental Disabilities Council.

This Executive Summary includes a brief review of our project, an outline of eight (8) major findings, and eight (8) major recommendations for action. The full report contains four chapters: 1. A Five-Year Plan of Action to Address Problems; 2. Defining the Population: A Profile of Aging Developmentally Disabled Persons; 3. Special Service Considerations and Obstacles to Serving Older DD Persons in Maryland; and 4. Lessons Learned and the Need for Collaboration.

Project Background

Our work was prompted by awareness of the increasing longevity, and the greater numbers, of citizens with developmental disabilities (DD) and mental retardation (MR). Research studies estimate that there are now between 200,000 and 500,000 older people with developmental disabilities in the United States, or at least five (5) out of every 1000 elders. The same research formula applied to Maryland means about 3000-4000 developmentally disabled adults over 60 in our state today.

Historically, adults with developmental disabilities spent much of their lives in large state institutions, or were cared for by their parents; in the latter instance care at home kept them out of the DD system of services. Moreover, a relatively short life-span prevented many DD and MR persons from

receiving service. Today adults with DD and MR are living longer and in many instances are outliving their parents.

The greater longevity of these citizens is creating a number of circumstances demanding attention. The more pressing include: two generation geriatric families comprised of older persons with DD and their non-DD parents; the threat of institutionalization, caused by the deaths of elderly parents, for adults with DD who have never participated in the DD service system; the prospect of sudden impact upon and demand for aging-related services by now-aging adults with DD and MR.

Basic Needs Identified by Project

The aging of citizens with developmental disabilities and mental retardation poses special challenges to the systems of services accustomed to meeting the needs of those with DD/MR or those who are elderly. On the one hand the DD system has not dealt historically with large numbers of clients who reach old age; on the other hand, the Aging Network of senior centers, etc., has had little experience with elders outside of the mainstream. Our project's research revealed that: (1) less than one-third of the older DD population receive state or local programs and services; (2) the demand for programs and services will increase; (3) overall there is a shortage of programs and services for DD and MR elders, the deficit occurring in both the Aging Network and the state DD system; (4) there has been very little history of meaningful interaction between the Aging Network and the DD system for planning or providing services; (5) there has not been a comprehensive statewide partnership to address coordinated services for the developmentally disabled and mentally retarded who grow old, although cooperation has developed since the inception of this project; and (6) without coordination, expensive duplicative dual systems of services may develop for DD

and MR elders. The need for coordination in planning and service delivery between the Aging Network and the DD system is basic. In the long run integrated services will cost less and be more effective.

DD System and Aging Network Services

The major DD service strategies designed to meet the needs of the adult DD population include: state mental retardation institutions (reduced in recent years because of deinstitutionalization); community-based independent living programs, including alternative living units, group homes, foster care, and small residential centers; day programs, including vocational training in a community environment, day rehabilitation, and supported employment; and individual support services so that DD adults can live with their families independently in the community. Medicaid programs partially support many DD adults in accordance with federal and state laws. All of these programs have very long waiting lists.

There are also some informal support programs operated by organizations such as The Association for Retarded Citizens, United Cerebral Palsy, Epilepsy Association, etc; their informal services may include counseling, information and referral, and family support. Extended family and neighbors may also serve as caregivers to DD elders, although this is not always predictable and consistent.

The Aging Network nationally is composed of the state unit, Area Agencies on Aging, and other aging-related service agencies in the local community. In Maryland the Aging network includes the State Office on Aging (OOA), Area Agencies on Aging (AAA), and the various community-based senior centers, adult day care sites, nursing homes, housing, nutrition, and transportation programs. Historically, the Aging Network has been oriented toward mainstream elders. Increasingly, it has been serving both healthy and non-DD frail elders. The several parts of the Network in Maryland have begun to include seniors who are

developmentally disabled. Medicaid is also a source of funding in the Aging Network for DD elders. Some DD elders receive assistance through local Departments of Social Services. There are also some informal support programs, including social and family service organizations, church related programs, mental health associations, and others that have recognized the needs of DD elders living in the community.

REVIEW OF PROJECT ACTIVITIES

Over the past fifteen months, the Aging and DD Research and Planning Project undertook a number of activities designed to identify the current status of DD/MR elders, their needs for services, barriers to those services, and the extent of existing services. We attempted to develop realistic solutions to identified problems, to share with others our findings, and to draw upon best practices existing elsewhere. Project activities tended to be related to four principal thrusts: Advisory Committees, Analyses, Coordination, and Outreach or Education.

Advisory Committees

(1) Developed strong, interactive Advisory Committees in Baltimore City and Montgomery County, comprised of leaders in DD/MR and in aging, to give us valuable insights into, and to delineate, needs, barriers and existing services. These committees were supplemented by related State Agencies, disability and aging providers, families of consumers, advocacy organizations, and others in the DD/Aging network.

(2) Convened four Advisory Committee meetings and two in-service workshops to obtain information, introduce the two systems to each other, and develop cooperative interaction between aging and developmental disability professionals.

Analyses

(3) Conducted a national search of state-of-the-art research studies, demonstration projects, and conference proceedings that were relative to **needs, barriers** and **existing services**; incorporated these findings into the planning process for services to developmentally disabled elders; and produced a written summary for our Advisory Committees, workshops, and others.

(4) Clarified current policy, regulations, funding sources, and local and state agency **barriers** related to identification, planning, and service provision.

(5) Conducted critical surveys of both the DD and Aging networks regarding **existing services** to older DD/MR clients; and developed a number of statistical studies and projections.

(6) Analyzed the need for leisure time services and retirement activities that are compatible with the changing interests of the elderly DD/MR population; and identified which of these services and activities can be integrated into ongoing programs.

(7) Explored a variety of alternative long-term living arrangements for this special population.

Coordination

(8) Encouraged cooperative planning efforts in Baltimore City in and Montgomery County for elderly DD persons.

(9) Worked with staff of the State Office on Aging (OOA) and the State Developmental Disabilities Administration (DDA) to develop cooperative policy and program initiatives.

(10) Encouraged the Developmental Disabilities Administration to hire a specialist in the area of aging and DD; the DDA's commitment resulted in additional surveys, statewide planning committees on aging and DD, and the first steps toward a cooperative agreement between DDA and OOA.

Outreach and Education

(11) Identified the need for special programming for this population, including access and integration into existing programs and services.

(12) Promoted deinstitutionalization and integration of DD elders into community programs and services.

(13) Presented our project's findings and suggestions for replication in other Maryland jurisdictions at a statewide conference in September 1986 for the Aging/DD network; the conference, attended by 300 professionals, included presentations by four national experts in aging and DD, with a focus on various models and best practices.

(14) Developed curriculum materials on the intersection of aging and DD; this curriculum was taught as a two-day credit course at the University of Maryland, College Park, during Summer 1986, and as a two-day non-credit course at the University of Maryland, Eastern Shore, during Fall 1986.

(15) Developed the **National Aging and Developmental Disabilities Information Exchange**, a clearinghouse of research studies, project reports and related materials which is computer accessible.

(16) Disseminated project findings broadly; activities included three journal articles about aging and DD, a workshop on aging and DD at the

statewide convention of the Maryland Association for Retarded Citizens, presentations at the 1986 and 1987 annual meetings of: the Gerontological Society of America in Chicago, the Association for Gerontology in Higher Education in Boston, the American Orthopsychiatric Association in Washington, the Southern Gerontological Society in New Orleans, and the Young Adult Institute in New York City.

(17) Submitted a proposal to the federal Department of Health and Human Services for a research translation and training project on aging and DD for the entire state of Maryland; the project's goals would include improved identification of client needs and strategies for insuring most appropriate levels of day care.

(18) Established a planning committee comprised of foundations and DD and aging organizations, in order to convene a national conference on aging and DD that will be held in June 1987 for state directors of aging and of DD and mental retardation.

PROJECT'S EIGHT MAJOR FINDINGS

Our project identified eight (8) major barriers or obstacles to providing programs and services to developmentally disabled and mentally retarded elders in Maryland. These barriers were identified through the work of our staff, advisory committees, consultants, and a 15-month review of current literature and model projects.

1. There is a need for more information, understanding, and sensitivity about the growing aging developmentally disabled population in Maryland. Professionals and the public are often unaware of the characteristics of this population, misconceptions and bias are widespread.

2. There is a need to develop information and services for the 1500-2500 developmentally disabled elders over age 60 in Maryland who are not known to the DDA or to other providers, agencies, and advocacy organizations. At present the Developmental Disabilities Administration serves fewer than 500 elderly DD citizens over age 60.

3. There is a need to clarify which agencies are responsible to serve the aging DD/MR population, the locus of services, and the implementation of services.

4. There is a need, outside the DDA and the State Office on Aging, for more aging-and-DD knowledge on the part of public officials and others who develop policy, e.g.. legislature, governor's office, DHMH, DHR, etc.

5. There is a need for policy initiatives for future programs and services, and for modification of existing federal and state regulations, with respect to older DD/MR citizens. Access to programs and services provided through the Older Americans Act is a concern.

6. There is a need for programs and services for this population. As long waiting lists grow, the competition for service among other vulnerable groups will increase. The Association for Retarded Citizens-Maryland estimates that more than 5000 DD and MR adults of all ages are on waiting lists for services in Maryland.

7. There is a need for additional funding to serve this population and initiatives to remedy this shortage. Many best practice examples are detailed in the **National Aging and Developmental Disabilities Information Exchange**.

8. There is a need to forge a partnership between the aging and DD networks, in order to redress knowledge gaps and to enhance staff skills. The Interagency Committee on Aging Services could serve as one part of this partnership.

PROJECT'S EIGHT MAJOR RECOMMENDATIONS FOR ACTION

#1. Educate professionals and the public that older persons with developmental disabilities are a special vulnerable population with specific characteristics and needs.

#2. Identify older developmentally disabled persons with particular emphasis upon addressing those whose needs are unserved.

#3. Clarify who is responsible for services, including the locus and implementation of these services; there needs to be recognition that administrators and programs often have difficulty stepping out of their historical identities.

#4. Educate state, regional, and county agencies about needs, barriers and existing services regarding older developmentally disabled persons, coordinate programs and services, and develop joint funding mechanisms among them.

#5. Change Federal and State policies and standards that may impede the provision of age-appropriate programs and services for older persons with developmental disabilities.

#6. Maximize existing programs in order to ensure an appropriate range of services to address the diverse needs of older persons with developmental disabilities.

#7. Innovate to modify current funding systems and to create new programs, so that adequate financial resources will be available for meeting the needs of older persons with developmental disabilities.

#8. Develop a network of training for paraprofessionals and professionals to enhance skills in aging and developmental disabilities in order to meet the needs of older persons with developmental disabilities.

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CHAPTER ONE

A FIVE-YEAR PLAN OF ACTION TO ADDRESS PROBLEMS

Our project, **Aging and Developmental Disabilities: Research and Planning**, assessed the status and problems of older developmentally disabled and mentally retarded citizens in Maryland. On the basis of that work, we offer eight, interrelated recommendations to address identified issues. These recommendations constitute a five year plan of action regarding what can be done in Maryland to plan for and serve older persons with developmental disabilities. We believe that the specifics that follow are both practical and reasonable; and, although these recommendations are ambitious, they can be accomplished if commitments are made by identified participants. The column on the left indicates which agency or body would be most appropriate to undertake the initiative and what year the recommendation should be implemented. Agency abbreviations are explained at the end of this chapter. Year one is fiscal 1988.

#1. Educate professionals and the public that older persons with developmental disabilities are a special vulnerable population with specific characteristics and needs.

DDA
OOA
Legislature
1-5

a. **Characteristics.** We recommend far greater understanding of Aging-and-Developmental Disabilities by professionals and the public. Aging DD persons are those who have life-long disabilities and are now age 60 or over. This includes individuals with mental retardation and non-retarded persons with developmental disabilities, including those who may be hearing impaired and/or visually impaired, and those with cerebral palsy,

epilepsy, and multiple disabilities, etc. For the first time in history many of these individuals are outliving their parents.

At the same time, we note that aging DD persons are in many respects like anyone else affected by aging. They need adequate and appropriate housing, day programs, family and community support programs, health and mental health services, and transportation. They may need long-term care. They also need case management or service coordination with strong advocacy.

DDA
OOA
Legislature
1-5

b. **Differences.** We recommend a greater sensitivity by professionals and the public to the differences among DD persons. There are basically two groups: Those who are similar to other older persons in many ways and can often be included in community-based generic[1] programs and services for all elderly persons; and those who are more severely disabled, who have complex health needs, and are less like other elderly persons. This second, smaller cohort of persons who are more disabled will need specialized programs and services. The point is that many elderly DD persons can be integrated with appropriate supports into a variety of senior programs. We are

---

[1] We often use the term generic programs and services. Generic means equal access for all citizens. For those individuals over age 60 generic means access to all senior and Aging Network services. Generic services for those persons over 60 may include those offered by Area Agencies on Aging, local Departments of Social Services, health departments, church groups, mental health associations, family service agencies, and other community groups.

encouraging integration. We are not recommending separate but equal services.

DDA
OOA
Legislature
1-5

c. **Bias.** We recommend a greater professional and public awareness about ageism and handicapism. Policymakers, program directors, providers, consumers, well and frail elders, and others should know the extent of stereotyping and restrictions commonly applied to older DD persons.

d. **Needs.** We recommend a greater understanding that older DD adults need adequate and appropriate human services, such as activities to occupy their day, an array of residential programs, a range of support services, accessible health care, accessible transportation, and nutritional assistance. Residential programs could include foster homes, group homes, group homes with nurses, intermediate care facilities, apartment programs, and other innovative residential alternatives. Day programs can include vocational programs, day activity programs, medical day programs, supplemental retirement programs, leisure and outreach programs, and senior citizens programs. Such settings need careproviders who are knowledgeable about the physiological, biological, social and emotional aspects of aging among developmentally disabled persons. Consequently, a major problem for program developers is to ensure that specially trained staff are present in such settings.

DDA
OOA
Legislature
1-5

e. **Diversity.** We recommend greater public and professional understanding of the diversity or heterogeneity of older DD individuals. There are vast differences among older DD persons with regard to physical, social and psychological characteristics. As we have noted, the majority of older DD adults should be part of the same service network that provides programs for other older adults. Those who are more severely handicapped should continue to receive specialized services from DD agencies and providers.

OOA
DDA
Higher education
Private sector
Religious groups
Advocacy groups
2-3

f. **Public Awareness.** We recommend greater education of the general public regarding informal support networks for aging and developmental disabilities; the mechanisms for this awareness may include continuing education through community colleges and adult education programs, public education forums by social, civic and religious organizations. We recommend that DDA and OOA cooperatively develop and disseminate an informative booklet about programs and services for DD elders in Maryland.

#2. Identify older developmentally disabled persons with particular emphasis upon addressing those whose needs are unserved.

Contracted
1-2

a. **Registry.** We recommend that the Developmental Disabilities Administration attempt to identify the approximately 2500 older DD persons not known in Maryland at present to DDA or other service providers, agencies and advocacy organizations. We recommend that the Developmental Disabilities Administration, in coordination

with other state and local agencies, maintain a registry of older DD persons. Without this additional information we will all continue to talk about numbers and not people in need of services.

DDC
ARC
DDA
Legislature
1-5

b. **Waiting Lists.** We recommend that state policy be modified so that long waiting lists are not continued. We echo the concerns of the State Association for Retarded Citizens and other community and advocacy organizations, and agree with them that long waiting lists are not productive. The older DD population in Maryland will double before the year 2020. This minority will increasingly compete with other elders for scarce long-term care programs and services. This problem, tied to long unreasonable waiting lists, must be addressed in this decade.

Public information campaign, media
Contracted
1-5

c. **Outreach to Consumers and Caregivers.** We recommend greater dissemination of information about existing programs so that older DD individuals, their families and caregivers, especially two generation geriatric families where DD adult children are outliving their parents, be informed of what is available to assist them in the State of Maryland. There needs to be greater public awareness that many older DD adults have remained outside the service systems, in the care of their parents. These caregivers are valuable but not inexhaustible resources among the various providers of care and services.

Consumers will benefit when caregivers become more aware of existing programs.

#3. Clarify who is responsible for services, including the locus and implementation of these services. There needs to be the recognition that administrators and programs often have difficulty stepping out of their historical identities.

All agencies listed in #3a 1-3

a. **Knowledge of Services by Agencies.** We recommend a better understanding of which agency or body is providing what services to older and DD citizens. There are many organizations concerned. A first step might be a detailed analysis of the similarities and differences between the services offered, coordinated or regulated by: the Developmental Disabilities Administration; The State Office on Aging; Area Agencies on Aging; The Interagency Committee on Aging Services; The Governor's Office for Handicapped Individuals; The Developmental Disabilities Council; The State Department of Human Resources and local DSS offices; the State Department of Health and Mental Hygiene including The Bureau of Services to the Aging, Maryland Medical Assistance Administration, the Mental Hygiene Administration, the Division of Health Regulations; the Division of Vocational Rehabilitation in the State Department of Education; County Government, City Government, community providers, other regional and local offices and programs. This analysis will assist staff members in a variety of state, local and private agencies to understand interrelated activities in various components of the service system. (see Appendix II)

State Agency or Contracted 2	b.	**Identify Gaps in Services.** We recommend defining the gaps in services to older DD persons, and clarifying who should fill them. These efforts should determine a cost-effective strategy for quality services. This initiative may be undertaken by one of the agencies identified in #3a, or may be contracted to an independent researcher.
Legislature DDA 1-5	c.	**Severely Disabled.** We recommend that those DD elders who are more severely disabled, who have complex health needs, and who are least like other elderly persons, continue to be served by the Developmental Disabilities Administration.
OOA AAA & other state & local government 1-5	d.	**Less Disabled.** We recommend that the majority of DD elders, those who are similar to other older persons, be included in the Aging Network's community-based generic programs and services, from information and referral to direct services.
OOA AAA 1-4	e.	**Incentives.** We recommend developing incentives for the Aging Network to serve older DD individuals and for the DD network to serve persons with late-life disabilities such as dementia. For example, the Job Partnership and Training Act and the Older Americans Act can be oriented to provide training for DD persons to become companions for old-old frail elders, or for healthy elders to serve as companions to DD elders.

#4. Educate state, regional, and local agencies about needs, barriers and existing services regarding older developmentally disabled persons, coordinate programs and services, and develop joint funding mechanisms among them.

All agencies listed in #3a
1-3

a. **Agency Priorities.** We recommend that state and local agencies in the DD and Aging networks begin to discuss their populations and priorities collaboratively in order to work together to better serve aging and DD persons. Each state agency is mandated to develop priorities for each fiscal year and some develop long-range plans. Each of these plans should reflect an understanding of the needs of a growing older DD minority.

All agencies listed in #3a
1-3

b. **Coordination.** On the basis of improved understanding of existing services and priorities, we recommend that these agencies jointly develop and maintain coordinated, non-duplicative programs and services to older DD persons. We recommend collaborative and coordinated linkages, cooperative relationships, interdepartmental training, and shared comprehensive generic programs and services designed to meet the needs of older DD citizens.

DHMH
OOA
All agencies listed in #3a
2

c. **Systematic Efforts.** We recommend the planning and establishment of a system of comprehensive assessments, programs and services for older DD persons that has strong linkages among all resources needed by this population. This system should include the generic services as well as the existing DD services. We recommend that, among the agencies listed in #3a, the Department of Health and

Mental Hygiene and the State Office on Aging take the lead in this initiative.

1-3

d. **Public-Private.** We recommend the strengthening of the public-private partnership within the state on behalf of aged DD persons, for example, in collaborative educational public relations and media efforts.

#5. Change Federal and State policies and standards that may impede the provision of age-appropriate programs and services for older persons with developmental disabilities.

National initiatives
1-3

a. **Federal Acts.** We recommend amendments at the national level to both the DD Act and the Older Americans Act so that the needs of persons who are aging and developmentally disabled will be more clearly focused in both acts. (see Appendix III).

All agencies listed #3a
1-3

b. **Access to Federal Programs.** We recommend a greater understanding by agencies that serve older or DD persons of how older DD persons can gain access to and benefit from various federal programs such as SSI, SSDI, Medicare, Medicaid, etc. These programs also have a significant impact at the state level.

DDA
DDC
2

c. **State Policy on Retirement.** We recommend the establishment of state policy so that older DD persons can retire with dignity. We recommend that the DDA and the Developmental Disabilities Council develop a joint position paper, with appropriate input from providers and

consumers, on retirement, productive leisure time, active generic community programming, and permanency planning.

DDA
DDC
3

d. **Full-Day Programming.** We recommend that the regulation for full-day programming for elderly DD persons participating in Developmental Disabilities Administration-funded community residential alternatives be changed so that as a matter of principle and practice, these individuals can choose to retire, semi-retire, or stay home some of the time, like other non-disabled seniors.

OOA
DHMH
DHR
Local government
1-3

e. **Access to Generic Programs.** We recommend that older DD persons have equal access to senior services, Aging Network programs, and other benefits accorded to elders by local community programs. We are not recommending wholesale age-integrated programming. That is, we are not, at this time, arguing that persons who are developmentally disabled and under age 60 be integrated into already crowded older Americans Act programs and services for senior citizens. On the other hand, easing of eligibility and service restrictions in Federal and State programs should be considered so that persons with disabilities who are age appropriate can be integrated into the generic services.

OOA
AAA
DDC

f. **Consumer Representation.** We recommend that at least one member of state and area DD advisory councils be a senior citizen with a developmental disability, a parent of a DD

Legislature
3

senior, or a sibling of an elderly DD person. Similarly, we recommend such representation within the state and area commissions on aging.

#6. Maximize existing programs in order to ensure an appropriate range of services to address the diverse needs of older persons with developmental disabilities.

Legislature
OOA
DDA
1-3

a. **Gateway I & II.** We recommend that Gateway I, administered by the Maryland Office on Aging as a single point of entry, contact, and outreach, be expanded to include information and services for older developmentally disabled persons, their families, and caregivers. The expansion of Gateway I and II to include older DD persons should emphasize long-term care, advocacy, tracking, and a clear statement of which agency or body is ultimately responsible to serve DD elders.

OOA
Legislative
All state agencies listed in #3a

b. **Expansion of Model Programs.** We recommend the continuation and expansion of joint funding mechanisms for older DD persons at the point of entry into the system and in all programs and services. As examples, in the area of transportation, there exists a state-funded, statewide program for elderly and disabled persons; also, sheltered housing for elderly persons currently accommodates some DD elders. We suggest that these models be developed in many other areas.

DHR
DDA
OOA

c. **Family Dwelling DD Adults.** We recommend that special attention be given to understanding the unique problems and pressures of those DD persons who have always lived

Federal Government
Local Government
1-5

with their parents and are now making a transition to community programs. We recommend long-range permanency planning, service coordination, and emphasis upon Individual Program Plans and quality assurance. Family and community supports as developed by the federal Administration on Developmental Disabilities and the state Developmental Disabilities Administration should be expanded.

DDA
DHR
OOA
1-3

d. **Joint Day Programs.** We recommend the continuation of joint day programs for aging DD persons and disabled older persons who may have dementia and Alzheimer's Disease. We also recommend the possibility of joint residential programs for persons with similar needs.

COA
1-3

e. **Multiple Strategies & Models.** We recommend an understanding that there is no one model for serving older DD persons. Our project has identified many alternatives, rather than a single model. At the same time we recognize that even some of the current best practice models may be time-limited: for the next generation of DD elders in the services system, i.e., those currently at mid-life, is more impaired than the present cohort. (The **National Aging and DD Information Exchange** provides information on a variety of projects and models and is available through the Center on Aging, University of Maryland, College Park, MD 20742.)

DDA
All agencies listed in #3a
1-5

f. **Leadership.** We recommend that the Developmental Disabilities Administration continue to be the lead agency for those older DD persons they are now serving, but that, whenever possible, services to future clients should have a community-based generic focus.

DDA
1-3

g. **Cross-Funding.** We recommend that the Developmental Disabilities Administration license and fund Aging Network programs, including adult day care, so that these programs can begin to serve DD adults currently supported by the Developmental Disabilities Administration.

Community Programs
1-5

h. **Interaction of Elders.** We recommend that non-DD elders have the opportunity for social interaction with DD elders. We recognize that such interactions have the potential to be mutually rewarding. For non-DD elders these relationships can develop social responsibility, self-satisfaction, volunteerism, and part-time employment.

#7. Innovate to modify current funding systems and to create new programs, so that adequate financial resources will be available for meeting the needs of older persons with developmental disabilities.

DDA
OOA
1-5

a. **Exchange of Services.** We recommend better use by the DD and aging systems of the services of the complementary system. Both systems have much to gain in this exchange. Less disabled DD/MR elders can be integrated into the existing array of senior services offered by the Aging Network. At the same time, formerly normal or mainstream elders who are now frail and disoriented can profit by participation in DD services. The DD system of day

programs, for example, is more attuned to dealing with non-normative behavior by combative or disoriented clients, behaviors that often spell exclusion of formerly mainstream elders from aging-related services like senior centers. Moreover, the DD system is accustomed to client staff ratios of 5 to 1 or even 2 to 1, numbers alien to the Aging Network used to dealing with ratios, in senior centers for example, of 200 or 300 to 1.

DDA 1-3

b. **Funding Following Clients.** We recommend that the Developmental Disabilities Administration support Aging Network services to older citizens with DD, so that these elders may participate in Aging programs and services. Some funds from the DD system need to "follow" clients to the aging system.

Contract 2

c. **Research on Funding Streams.** We recommend that an RFP be issued for a study that will help develop an understanding of what state and local generic funding streams are now available and what new ones can be developed. For example: Can dollars be shifted from programs to persons or from one system to another?

State Legislature 1-3

d. **New Residential Options.** We recommend the development of 25 new residential living options, including group homes and/or ALUs, to serve at least 100 persons over the next 3 years; some of these residences should include older persons with disabilities that are not developmental disabilities. Although 100 persons do not represent five

percent of the 2000-3000 unserved DD elders, such an action would begin to operationalize a system that is sensitive to the needs of a growing number of DD elders whose parents and families will no longer be able to care for them.

AAA 1-3

e. **Support Services.** We recommend that support services to older people with developmental disabilities be developed so that DD elders can participate in senior centers and other aging programs. Such support services might include creative use of Older American Act Title V monies for senior aides and companions for DD/MR elders.

Contracted 2

f. **Study of Retirement Effects.** We recommend that the Developmental Disabilities Administration, in cooperation with the State Department of Budget and Fiscal Planning, study how the retirement of older DD persons from sheltered and competitive employment will effect the size and cost of existing community programs.

DDA

g. **Retirement Residences.** We recommend that the several agencies and groups identified in #3a explore the possibility of developing retirement residences or communities exclusively for DD/MR elders. These elders need to be able to make a comfortable transition from work-oriented day programs to retirement, and a sheltered retirement community may be a meaningful option. Such a venture is now being developed by Lutheran Social Services in the Saginaw, Michigan area.

#8. Develop a network of training for paraprofessionals and professionals to enhance skills in aging and developmental disabilities in order to meet the needs of older persons with developmental disabilities.

Contracted

1-2

a. **Cross-Training.** We recommend cross-system training in at least the following content areas: organization and practices of the aging and DD service systems; ageism and handicapism attitudes, myths and stereotypes; physiological, psychological, emotional, social aspects of aging, especially for direct care providers. Training should be targeted to various levels of personnel, including state directors, managers, providers, case managers, and service coordinators. We recommend, further, that training focus upon the **intersections** of aging, disabilities, and the human services more comprehensively. That is, training should focus upon those points where need, expertise and client characteristics intersect. Training should be complementary, that is, cross-disciplinary, generic, and holistic in order to ensure improved quality programming and better service coordination. There is the need for leadership in integrated aging-DD expertise in order to provide this training. The current project has enabled the University of Maryland Center on Aging to begin to develop this comprehensive expertise.

Legislature

Higher education

1-2

b. **External Support.** We recommend identifying funding sources to support training and the development of an integrated aging-DD expertise. The needs for training are substantial and can best be met through continuous,

developmental efforts. These are likely to require support from sources inside and outside the traditional array of provider agencies.

DDA
OOA
COA
1-2

c. **Training Curriculum.** We recommend that the Developmental Disabilities Administration, State Office on Aging, and the Center on Aging at the University of Maryland develop and implement a training curriculum on the intersections of aging, developmental disabilities, and human services.

MSDE
Higher education
3-5

d. **Educational Curriculum.** We recommend that gerontology programs incorporate information about developmental disabilities and that disability programs incorporate information about aging in both high schools and higher education, including preparation in special education and rehabilitation.

Contracted
2-3

e. **Exchange Internships.** We recommend greater exposure to the operations of complementary service systems. This may be accomplished through limited internships in or staff exchanges between agencies in aging and agencies in developmental disabilities. These experiences would benefit all levels from managers to direct service providers in state, regional, and local offices.

Higher education
2-3

f. **Professional Schools.** We recommend that professional schools develop internships and exchanges for their students to work with DD elders in various contexts. Appropriate professional schools might include social work, special education, nursing, rehabilitation,

medicine, occupational therapy, physical therapy, and family studies.

Agencies cited in this chapter include: Area Agency on Aging (AAA), Association for Retarded Citizens (ARC), The University of Maryland Center on Aging (CoA), Developmental Disabilities Administration (DDA), Maryland State Planning Council for Developmental Disabilities (DDC), Department of Social Services (DSS), Department of Health and Mental Hygiene (DHMH), Department of Human Resources (DHR), Maryland State Department of Education (MSDE), and Maryland State Office on Aging (OOA).

CHAPTER TWO

DEFINING THE POPULATION: A PROFILE OF AGING DEVELOPMENTALLY DISABLED PERSONS

Introduction

There are between 200,000 and 500,000 older people with developmental disabilities in the United States, or at least five (5) out of every 1000 elders. Increasing numbers of the elderly persons with developmental disabilities are being cared for by their aging parents, and this two-generation geriatric family situation poses special challenges to the future of existing programs and services. For the first time in history, adults with developmental disabilities are beginning to outlive their parents. Today the number of older developmentally disabled persons over 60 in Maryland is estimated to be 3000 to 4000 persons, only a small percentage of whom are currently known to be served in state-funded programs.

In the following pages we offer brief explanations of developmental disabilities and aging; and estimates of the numbers of older DD persons, their characteristics, and experiences with programs and services. This chapter is organized into four main sections: definitions and characteristics of developmental disabilities; definitions and characteristics of aging, including the intersection of DD and aging; numbers and prevalence in Maryland; and served versus unserved persons in Maryland.

WHAT ARE DEVELOPMENTAL DISABILITIES?

A developmental disability as defined by PL 95-602, as amended, is a severe, chronic disability which is attributable to a mental or physical impairment or

combination of mental and physical impairments that manifest before age 22, which is likely to continue indefinitely and results in at least three substantial functional limitations, and which reflects the person's need for a combination of services that are lifelong or of extended duration. Developmental disabilities (DD) include mental retardation, cerebral palsy, blindness, deafness, orthopedic handicaps, multiple disabilities and other life-long disabilities. The definition of developmental disabilities in the Health General Article, Title 7, of the Annotated Code of Maryland is substantially the same as the federal definition.

The term developmentally disabled includes persons with mental retardation and non-retarded developmentally disabled persons. Mental retardation is defined as significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, manifested during the developmental period.

Adaptive behavior is defined as the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for age and cultural group. There is much behavioral variability among different individuals who have similar IQ scores reflecting their individual development, schooling, adult responsibilities, etc. Many mildly retarded persons are often not considered retarded in certain environments.

Low levels of adaptive behavior are related to institutionalization and lack of opportunities for normal life experiences and activities. Today, many younger developmentally disabled persons work competitively and live in relative independence with their family or in group homes. Historically this was not the case; as a result many developmentally disabled persons who are today 60 years old and over have not had the opportunity to work, to live relatively

independently, to attend school for more than a few years, and to develop interpersonal relationships.

Non-retarded developmental disabilities include a number of life long developmental handicaps such as deafness, blindness, seizures or epilepsy, cerebral palsy, spina bifida, muscular distrophy, neurological impairments, emotional disorders, speech and language disabilities, and other multiple disabilities.

WHAT IS AGING?

Robert Atchley (1983) defines aging as "...a broad concept that includes physical changes that occur in our bodies over adult life, psychological changes in our minds and in our mental capacities, and social changes in how we are viewed, what we can expect, or what is expected of us." Various other perspectives or measures on aging include the chronological, developmental, functional, sensory, psychomotor, and spiritual. Older developmentally disabled individuals, like their nondisabled peers, are affected by physical, psychological, social, and other changes.

What Is The Meaning Of Old?

Robert Butler (1976) writes that "when we talk about old age, each of us is talking about his or her own future." The meaning of "old" depends upon the perspective taken. Richard Kalish (1982) writes that old can be defined: chronologically (attainment of a certain age); legally and economically (retirement, Social Security, Medicare); physically (posture, gait, voice, ability to hear and see); organically (forgetfulness, slower motor behavior); in terms of social roles and relationship to others (degree of interaction, communication); and by self-report (as when an individual says, "I guess I'm

old."). In practice, Kalish argues, " most of us shift our definitions of old to suit the occasion, often without fully realizing what we are doing."

In personal terms one may be invited to join the American Association of Retired Persons at age 50. One qualifies for programs under The Older Americans Act on reaching age 60. So one can attend senior centers, nutrition programs, and other community activities at 60. At 65 a person becomes eligible for full Social Security benefits and for Medicare coverage; and 65 is used for many income and health care programs.

How Many People Are Old?

Twenty eight million Americans were 65 years of age and older in 1986, representing 11.9% of the population, or almost 1 in every 8 citizens. The number of Americans 65 and over has increased by 10% since 1980, as compared with a 4% growth rate of those under 65. The older population itself is getting older, with particularly rapid growth of those over 75 and 85. By the year 2030 there will be about 65 million people over 65 or 2-1/2 times their number in 1980.

Research shows that most old people are well. Gerontologists distinguish between well/normal and frail/disabled; the latter includes functionally impaired elderly and those with late-life disabilities. Eighty to 85 percent of the population over 60 is well vs. 15% to 20% being frail and disabled. This gerontological use of the terms disability and late-life disabilities does not usually refer to elders who are developmentally disabled, or life-long disabled.

AGING AND DEVELOPMENTAL DISABILITIES FROM A TO Z

The following information is as close to a state-of-the-art review of the intersections of aging and developmental disabilities as exists in 1987.

(A) The life histories of most aging and elderly developmentally disabled individuals are generally very different from their non-disabled peers. Most have had little education, have been isolated from normalized life experiences, have had few relationships outside "handicapped" peer groups or their families.

(B) Even so, older developmentally disabled citizens have much in common with other elderly people as they grow older. Programming options can include remaining with younger DD persons, integrated generic services, specialized services for older DD persons, and active structured retirement. Most easily adjust to generic senior programs.

(C) Two groups of developmentally disabled citizens can be distinguished: aging developmentally disabled persons who are 55 to 64, and elderly developmentally disabled persons 65 or older.

(D) There is considerable disagreement as to how many citizens with DD are aging and elderly. Estimates range from 200,000 to 500,000. The aging DD population may double by 2020. At least five out of every 1000 persons over 60 have a life-long developmental disability.

(E) Like all elderly persons, older developmentally disabled citizens are a growing and heterogeneous group. Permanency planning, programs, and services should reflect this heterogeneity.

(F) Various less restrictive supportive service alternatives and opportunities need to be explored in place of institutionalization. More restrictive settings encourage less adaptive skills and greater dependency. It is important to encourage the continued development of community activities so that developmentally disabled persons can choose active retirement.

(G) For the population of the older developmentally disabled, programs, services, and funding sources are incremental, fragmented, categorical, and confusing. There is a need to stimulate high quality, interagency, coordinated, collaborative program development.

(H) Developmentally disabled older citizens share many of the same medical conditions and impairments, and have many of the same chronic health problems as other older people. Cardiovascular conditions top the list, followed by motor, self-care, and other functional impairments.

(I) Many older developmentally disabled persons are relatively high functioning, able to communicate, free of maladaptive behaviors, in good health, and do not look disabled. Functional limitations may increase with age as they do with most older person and they may supersede chronological age as a cause of frailty.

(J) Older developmentally disabled people are often in double jeopardy and are often not able to advocate for themselves. Their parents or caregivers, now into their 70s and 80s, historically have often been active advocates. The development of advocacy for this population should be addressed.

(K) Two generation geriatric families are becoming the rule when older DD persons live with their families, but the DD son or daughter is increasingly out-living his or her elderly parents. This two-generation geriatric family poses special challenges to programs and services in DD and aging.

(L) If the older developmentally disabled population is incorrectly perceived already to have a support network within institutional or community systems, many people will assume this population is already being served.

(M) Structured living arrangements that encourage the development of informal support networks and encourage use of community health and social services, thus allowing for continued independent living, have not been explored to a great extent for older developmentally disabled people.

(N) Community living options for this population include home care, foster/personal/family care, group homes, supervised apartments, shared housing, boarding homes, sheltered housing, and nursing homes. These options can occur through DD and aging services, separately, or through a combined network.

(O) Community living promotes independence, health, skill maintenance and development, relationships with peers, and access to generic programs and services. Access to and participation in leisure activities, positive adaptive behavior skills, and access to generic programs and services are promoted in community-based programs.

(P) There is a growing knowledge base on how to train professionals and paraprofessionals to work with this population.

(Q) There is great confusion regarding the difference between long-term mental illness and developmental disabilities as both populations age. Older DD people do have mental health needs which in many cases are similar to the general population. These needs may be exacerbated as persons with developmental disabilities age.

(R) Some Aging Network personnel and some developmentally disabled system personnel refrain from becoming involved in addressing the problem of the older developmentally disabled because they overestimate the difficulties in solving the problem.

(S) Too many elderly DD persons live in institutions. Emphasis should be on deinstitutionalization and policies that promote stability and permanence.

(T) Financial and permanency planning for the future should become the rule for aging and elderly DD persons. Otherwise, when older parents die or

can no longer care for them, in the midst of crisis institutionalization may be seen as the only alternative.

(U) The stigma of aging and developmental disabilities can be particularly threatening to frail and well elderly persons who are anxious about their own cognitive capacities and ability to function competently. Some elderly DD persons may be more similar to old-old frail persons when distinguished from young-old persons.

(V) Various models of respite care, including adult day care, need to be explored for the older adult with developmental disabilities.

(W) Those elderly DD persons who live at home with parents need or will eventually need permanent supervised and structured long-term care in community-based programs. Their parents will not live forever.

(X) The number of older DD clients on waiting lists, and the time they remain on residential and day waiting lists, must be explored. Institutional placement is not the only alternative, even in the midst of crisis.

(Y) Most older DD persons now in large public institutions do not need to remain there. It must be recognized that state-run institutional life has created a complex group of problems. Deinstitutionalization of these persons will be very complex, as well, and the solution should not simply be the uniform and often inappropriate transfer to nursing homes.

(Z) State leaders in the aging and developmental disabilities network should work together to develop a highly effective and mutually beneficial partnership to serve the growing aging and DD population.

HOW MANY ELDERLY IN MARYLAND?

In Maryland, in 1985, according to the State Office on Aging, 15.2% of the state's population was 60 or over. By the year 2005 this will increase to nearly 20% or 940,703 people. According to the 1985 Census, 665,775 Marylanders were over 60 and 460,087 were 65 or older; 179,967 were 75 or older and 41,145 were 85 or older. The age structure of the elderly population in Maryland is shifting, with a lower proportion aged 60-64 and a higher proportion aged 80 and above projected for the near future.

How Many Older Marylanders Are Disabled?

One measure of disability is the inability to perform "activities of daily living" (ADL) without assistance. These activities are those that people perform

habitually and universally (bathing, dressing, eating, toileting, housework, shopping, etc.) In Maryland in 1983 the majority of noninstitutionalized elderly age 65 + were not disabled. Of the total elderly population, 20.4% were mildly disabled, 7.2% were moderately disabled and 7.8% were severely disabled. The prevalence of functional disability in the elderly population may increase in future years.

How Many Older Marylanders Are Developmentally Disabled?

In most states, including Maryland, the number of older developmentally disabled persons is considered to be proportional to the overall number of older persons in the state. Experts differ as to what the frequency rate is for DD/MR among older persons, and what chronological age should signify "old." Prevalence figures currently range from 1.2% to 2.4%, and the onset of old has been pegged variously at ages between 40 and 65 years for the DD/MR population. National estimates using 1.2% to 2.4%, and age 60 translate into 200,000 to 500,000 older DD citizens in the United States. This research formula means that Maryland has between 3000 and 4000 developmentally disabled and mentally retarded aging persons over age 60 today. As we discuss in the next section, these figures are considerably lower than the projections of the Maryland State Plan. National projections indicate that the number of DD elders will more than double over the next 30 years.

The 3000-4000 developmentally disabled and mentally retarded aging persons over 60 in Maryland include:

151	persons reside in State MR institutions.
315	persons attend community day programs financed by Developmental Disabilities Administration. (299 out of this 315 live in community residential programs contracted by Developmental Disabilities Administration)
466	**SUBTOTAL** served by Developmental Disabilities Administration

100	are served by the aging network in a variety of programs.
300	over age 46 live in Nursing Homes
100	are served by DSS, family service agencies, health, housing and multi-service agencies.
50	are served by mental health organizations, family support groups, and churches.
550	**SUBTOTAL** served by non-DDA providers
344	non-retarded developmentally disabled persons over 51 are unserved and have been identified by a community needs survey conducted by the Walter P. Carter Center
171	mentally retarded persons over 51 are unserved and have been identified by a community needs survey conducted by the Walter P. Carter Center
515	**SUBTOTAL** identified as unserved
1500	approximate cumulative **SUBTOTAL** of identified served and unserved
1500-2500	live with their families or in some other type of care setting and are not known to any of the service systems.
3000-4000	**TOTAL** older developmentally disabled persons in Maryland

ESTIMATING PREVALENCE OF DEVELOPMENTAL DISABILITIES IN MARYLAND

According to the Maryland State Plan for Developmental Disabilities, Fiscal years 1987, 1988, and 1989, "there exist no data on the actual prevalence of developmental disabilities in Maryland based on the federal definition; however, application of national prevalence rates to state population data yields useful estimates for planning purposes."

The Maryland State Plan notes that "Tables 1.1, 1.2, and 1.3 provide information on the estimated number of noninstitutionalized developmentally disabled residents in Maryland by age and by geographic division, or county. These estimates were obtained by applying age-specific prevalence rates developed by Gollay and Associates to interpolations of population projections developed by the Maryland Department of State Planning, Office of Planning Data, based on 1980

Census population counts. All numbers have been rounded to the nearest ten persons, thus emphasizing that they are, indeed, estimates."

One should note that the Maryland State Plan makes projections for all ages. These figures are generally based on a relatively low and conservative 1.2% prevalence rate for Maryland. As we have noted above, other studies argue that the rate is double, or 2.4 percent of the total population. Our project staff believes, however, that the latter is an inflated figure and true general population prevalence lies closer to the 1.2% rate, while the prevalence among elders is about five per 1000.

Our own research and planning study over the past eighteen months reinforces that there are between 3000 and 4000 developmentally disabled persons over 60 in Maryland. We believe these figures are closer to actual prevalence in Maryland than the following higher estimates derived from the State Plan (Tables 1.1, 1.2, 1.3). Legislators and planners should be aware of the variance among professional projections, and should be open to the possibilities that prevalence rates within their jurisdictions may meet or exceed the figures in the following tables. Studies prepared by our project's research assistant Florry Berkley are in basic agreement with the following tables. Studies by our consultant, Dr. Matthew Janicki, are more in agreement with our own later estimates of 3000 to 4000 developmentally disabled citizens over 60 in Maryland. (See Janicki and Wisniewski, Planning for an Older Developmentally Disabled Population, 1985.)

TABLE 1.1 DEVELOPMENTALLY DISABLED POPULATION IN MARYLAND: FY 1987 ESTIMATES BY AGE AND GEOGRAPHIC SUBDIVISION

GEOGRAPHIC SUBDIVISION	STATE POPULATION		DEVELOPMENTALLY DISABLED POPULATION BY AGE GROUPS				
	TOTAL	PERCENT MINORITY	TOTAL	PRESCHOOL 0 - 5	SCHOOL AGE 6 - 21	ADULT 22-64	OLDER ADULT 65+
STATE	4,429,831	26.5	49,910	2,740	23,180	15,880	8,110
ALLEGANY	78,746	2.3	910	40	380	260	230
ANNE ARUNDEL	405,064	14.8	5,310	250	3,000	1,500	560
BALTIMORE CITY	753,358	59.8	8,560	500	3,750	2,530	1,780
BALTIMORE COUNTY	664,510	12.8	7,220	360	2,950	2,440	1,470
CALVERT	42,303	19.7	480	30	240	150	60
CAROLINE	24,337	17.0	290	20	120	80	60
CARROLL	112,121	3.8	1,240	70	590	410	170
CECIL	65,866	5.9	760	40	370	230	120
CHARLES	87,009	26.1	990	60	540	300	90
DORCHESTER	30,768	30.2	360	20	150	100	90
FREDERICK	131,484	6.3	1,490	90	730	460	210
GARRETT	27,808	0.6	330	20	160	90	60
HARFORD	158,796	10.5	1,750	100	850	590	210
HOWARD	149,230	16.6	1,580	90	760	580	150
KENT	16,686	22.5	200	10	80	60	50
MONTGOMERY	638,237	16.2	6,970	380	3,070	2,330	1,190
PRINCE GEORGE'S	681,068	45.8	7,420	450	3,630	2,520	820
QUEEN ANNE'S	29,425	14.4	320	20	140	100	60
ST. MARY'S	66,989	17.5	750	50	380	230	90
SOMERSET	19,627	35.7	220	10	100	60	50
TALBOT	27,141	20.4	300	10	110	90	90
WASHINGTON	116,424	5.7	1,310	60	580	410	260
WICOMICO	69,055	23.4	770	40	340	240	150
WORCESTER	33,775	25.6	380	20	160	120	90

GEOGRAPHIC SUBDIVISION	STATE POPULATION		DEVELOPMENTALLY DISABLED POPULATION BY AGE GROUPS				
	TOTAL	PERCENT MINORITY	TOTAL	PRESCHOOL 0 - 5	SCHOOL AGE 6 - 21	ADULT 22-64	OLDER ADULT 65+
STATE	4,467,266	26.6	49,280	2,760	22,070	16,060	8,390
ALLEGANY	78,686	2.3	910	40	370	260	240
ANNE ARUNDEL	409,932	14.9	4,450	250	2,080	1,530	590
BALTIMORE CITY	751,275	60.2	8,540	500	3,710	2,530	1,800
BALTIMORE COUNTY	665,299	13.2	7,220	360	2,900	2,440	1,520
CALVERT	43,590	19.3	490	30	240	150	70
CAROLINE	24,538	16.9	280	20	120	80	60
CARROLL	114,308	3.8	1,260	70	590	420	180
CECIL	66,628	5.8	750	40	360	230	120
CHARLES	89,333	19.9	1,020	70	540	310	100
DORCHESTER	30,828	30.2	350	20	140	100	90
FREDERICK	133,951	6.2	1,500	90	730	470	210
GARRETT	28,094	0.6	330	20	160	90	60
HARFORD	160,287	10.5	1,750	100	830	600	220
HOWARD	154,302	16.9	1,620	90	760	610	160
KENT	16,697	22.5	200	10	80	60	50
MONTGOMERY	648,294	16.4	7,080	390	3,080	2,360	1,250
PRINCE GEORGE'S	684,595	46.3	7,420	450	3,570	2,550	850
QUEEN ANNE'S	30,046	14.0	340	20	140	110	70
ST. MARY'S	68,242	17.4	770	50	380	240	100
SOMERSET	19,999	35.9	230	10	110	60	50
TALBOT	27,305	20.3	300	10	110	90	90
WASHINGTON	117,068	5.7	1,320	80	580	410	270
WICOMICO	69,752	23.5	770	40	340	240	150
WORCESTER	34,217	25.4	380	20	150	120	90

TABLE 1.3 DEVELOPMENTALLY DISABLED POPULATION IN MARYLAND: FY 1989 ESTIMATES BY AGE AND GEOGRAPHIC SUBDIVISION

GEOGRAPHIC SUBDIVISION	STATE POPULATION		DEVELOPMENTALLY DISABLED POPULATION BY AGE GROUPS				
	TOTAL	PERCENT MINORITY	TOTAL	PRESCHOOL 0 - 5	SCHOOL AGE 6 - 21	ADULT 22-64	OLDER ADULT 65+
STATE	4,509,620	26.8	49,530	2,790	21,860	16,240	8,640
ALLEGANY	78,672	2.3	910	40	370	260	240
ANNE ARUNDEL	415,142	15.1	4,480	260	2,050	1,550	620
BALTIMORE CITY	749,998	60.6	8,510	500	3,660	2,530	1,820
BALTIMORE COUNTY	666,831	13.6	7,230	370	2,850	2,440	1,570
CALVERT	44,984	18.9	510	30	250	160	70
CAROLINE	24,758	16.8	280	20	120	80	60
CARROLL	116,638	3.8	1,270	70	590	430	180
CECIL	67,435	5.8	770	40	360	240	130
CHARLES	91,826	19.6	1,030	70	540	320	100
DORCHESTER	30,903	30.2	350	20	140	100	90
FREDERICK	136,558	6.2	1,520	90	730	480	220
GARRETT	28,385	0.6	320	20	150	90	60
HARFORD	161,961	10.6	1,750	100	810	610	230
HOWARD	159,750	17.2	1,660	100	760	630	170
KENT	16,706	22.4	190	10	70	60	50
MONTGOMERY	659,003	16.7	7,190	390	3,090	2,400	1,310
PRINCE GEORGE'S	688,931	46.8	7,430	450	3,520	2,570	890
QUEEN ANNE'S	30,701	13.8	340	20	140	110	70
ST. MARY'S	69,578	17.4	770	50	380	240	100
SOMERSET	20,425	36.1	240	10	110	70	50
TALBOT	27,490	20.2	300	10	110	90	90
WASHINGTON	117,754	5.7	1,310	60	570	410	270
WICOMICO	70,449	23.6	760	40	340	250	160
WORCESTER	34,692	25.2	380	20	150	120	90

MORTALITY RATES

According to Lubin & Kiely (in Janicki & Wisniewski, 1985) life expectancies for the MR population are lower, and mortality rates are higher, than in the general population, at earlier and later ages. The non-retarded DD population, however, is much more similar to the larger, "mainstream" aging population. In addition, life expectancies are increasing and a larger proportion of MR adults now in their middle years should be expected to survive to older age. Among the mentally retarded higher mortality rates have typically been found among males, persons with more marked MR, non-ambulatory persons, and institutionalized residents.

MARYLAND'S UNSERVED OLDER DD POPULATION

There is substantial statistical research and data, supported by additional informal surveys and interviews conducted by our project and the Developmental Disabilities Administration in 1986, that indicate that there are at least 2000 unserved, and for the most part unknown, developmentally disabled citizens over 60 in Maryland. The numbers unserved are estimated to range from 2000 to 3000. That is why we have recommended a state registry, information and referral services, and proactive planning for this population. In general these 2000-3000 individuals have never been part of any aging or disability service system and are unknown to the aging or DD networks. Many of them have lived their entire lives with parents who have been their primary caregivers and their primary source of companionship and socialization. For the most part their parents never expected that their developmentally disabled adult children would live to late life. As these DD adult children continue to outlive their elderly parents, they will need an array of long-term care settings, programs and services, so that they can live their final years with dignity and respect as part of the community where they have lived their entire lives.

Maryland is fortunate to have conducted the Community Needs Survey in 1985. This survey identified approximately 500 older mentally retarded and developmentally disabled citizens over 60 living in the community. It focused on a variety of demographic characteristics of these clients and caregivers, identified clients living at home with their families who are at risk of institutionalization, and investigated factors contributing to stress in the family and the urgency of need for residential placement. These studies were conducted by principal investigators Michael Sachs, Ph.D., and Michael Smull of the Applied Research and Evaluation Unit, Developmental Disabilities Program, Walter P. Carter Center, University of Maryland School of Medicine.

As we have indicated earlier, the State Developmental Disabilities Administration serves almost 500 DD persons over 60 in institutional and community programs, non-DDA providers serve approximately 500 other DD elders. and another 500 DD elders have been identified as unserved. These three figures can be combined, but there still remain at least 1500 unserved and unknown older DD citizens in Maryland over 60. In short, by conservative estimates two-thirds of Maryland's senior citizens who are developmentally disabled remain unserved. Again, figures in Tables 1.1, 1.2., and 1.3 indicate that we could be underestimating this unserved population substantially.

Three Clusters in Maryland

In Maryland we can distinguish three clusters or groups within the older developmentally disabled population. The first cluster is the most disabled and often multiply disabled. It includes severely and profoundly mentally retarded persons with significant health problems, and non-retarded DD citizens with multiple physical disabilities and related health problems. Some of these individuals are institutionalized. A second much larger cluster includes

individuals with a wide range of disabilities, including persons who may participate in day and residential programs administered by the Maryland DDA, and those who live with their parents but are often isolated from other social interaction, and may or may not participate in DDA-sponsored programs and services. Some of these individuals may use public transportation or para-transit systems. They range from being significantly independent to having few independent living skills. A third cluster represents individuals who may have been partially assimilated into society through schools and employment. They may have been served throughout life or sporadically by various public and private social and family service agencies. As they mature into their 50s and 60s, many of these individuals will need more services as they make the transition into late adulthood.

With regard to the numbers of individuals receiving services from DDA, the first cluster, for the most part, has received life-long services. It comprises about one-third of those who are 55 or older and are served by DDA. The second cluster overall is served much less by DDA because of long waiting lists of persons who need services but remain unserved. This cluster comprises about two-thirds of those who are 55 and older served by DDA. It is important to note that the vast majority of the second cluster have never received services from DDA and live at home with elderly parents. They may receive some generic services from churches, mental health associations, family service agencies, local departments of social services, medical and mental health programs, and the Aging Network after age 60. The third cluster, unserved by DDA, will need access to all of the services mentioned beginning in their 50s and 60s. They will place a heavy burden on the long-term care system in the very near future. It is the remainder of the second cluster (those currently unserved by DDA) plus the third cluster that are the focus of our project.

RESULTS OF OUR DD AND AGING SURVEYS

In an effort to determine the scope of services available to and utilized by older DD persons in Baltimore City, Baltimore County, and Montgomery County, our project conducted two brief pilot surveys. We hoped to identify both the gaps in services for this population and the links that may be possible between the DD and Aging/human services networks.

One survey (the DD survey) was mailed to 19 DD service provider agencies in the three jurisdictions. Fourteen (74%) were returned. The other survey (the Aging survey) was mailed to a very broad array of 238 aging/human service agencies that included nursing homes, senior centers, religious organizations, and adult day care facilities. Only 49 (21%) responded.

The DD Survey

a. Numbers and Characteristics of Clients. The DD pilot survey makes it apparent that the aging DD population served by the DD network will be growing considerably in the next 20 years, as the number of persons being served in the 45-59 bracket is approximately three and a half times greater than that in the 60+ bracket. The number of persons on waiting lists for the younger group is two and a half times greater than that of the older group. The agencies responding to our survey described many different functional levels for their clients, the totals being slightly skewed towards those individuals in the moderate to severe levels of impairment, particularly in the areas of self care and capacity for independent living.

b. Programs. The results of the survey show that while the majority of DD service providers do not at present have special programs for their aging DD clients, nor have they had such programs in the past, approximately 2/3 are planning them for the future. Specific plans include group homes for seniors,

medical day care facilities, and the tailoring and/or expansion of existing activities for aging clients.

According to the results of the survey, very few DD clients in the 45-59 age range participate in aging-specific programs, while approximately 18% of the 60+ population go to senior centers on a part-time basis. About 30% of the younger group and 20% of the older group utilize some sort of generic community service (recreation, health and dental services, mental health counseling, and religious services and classes.)

c. Problems. There were a variety of responses to the questions about past and present problems and what future help will be needed to serve this growing population. Expanded (or start up) senior activity programs and increased funding were the most often cited issues. It was suggested by several respondents that funding follow the client rather than being allocated by program. This would allow for a continuum of services enabling clients to move more easily as their needs change. Increased staff training, more medical staff, greater generic resources, and additional transportation were mentioned by several agencies. One respondent suggested that there should be a general rethinking of goals and objectives appropriate for older DD persons.

The Aging Survey

a. Numbers and Characteristics of clients. The aging survey covered a broader range and greater number of agencies with most of the responses coming from such clearly identifiable "aging" entities as senior centers, nursing homes, and adult day care facilities. However, of those surveys returned, over half were serving no aging DD clients.

Aging DD clients served in the aging/human services network are spread among the various age ranges with the majority being over 60. Functional levels vary,

with economic self sufficiency, capacity for independent living, and self direction tending to be on the lower end of the continuum and receptive language on the higher end. The majority of clients live in sheltered housing, nursing homes, and at home, with the minority residing in housing for the elderly.

b. Programs. The great majority of agencies neither currently have nor have had any special programs for aging DD clients. However, as with respondents to the DD Survey, many are planning to serve this population in the future. Additional adult day care and integration into existing regular programs were mentioned as future plans.

c. Problems. Transportation and difficulties with the families are the most frequently reported problems in serving this population. Other problems mentioned were: acting out behavior, health problems, acceptance by other non-DD clients, difficulty understanding the speech of DD persons, inadequate staff, and payment for services not covered by Medicare. Lack of funding and staffing are the most frequently mentioned barriers to serving DD clients in the future. Other barriers listed were: lack of stimulation, lack of resources for special adaptive equipment, and lack of staff training.

In addition to these two informal surveys conducted by our research and planning project, M. Doreen Croser, Assistant Director, Developmental Disabilities Administration, developed a short survey for DD agency directors in October 1986. She obtained a good response rate and her survey's results are available from the Developmental Disabilities Administration.

CHAPTER THREE

SPECIAL SERVICE CONSIDERATIONS AND OBSTACLES FOR SERVING OLDER DD PERSONS

Background

The developmentally disabled segment of our older population has become a national concern for a number of reasons. First, there is widespread uncertainty about the actual numbers of DD elders, as many have lived with their parents at home and have not interacted with the DD or aging service systems. Second, there is evidence that while this population is steadily increasing, there is no coherent public policy at state and national levels to address the greater demand for services. Third, the developmentally disabled appear to make up a disproportionate share of institutionalized elderly persons. Fourth, many DD elders are in transition from work-oriented programs to retirement activities, and money needs to be stabilized to provide for related services.

WHAT IS THE BEST DEFINITION OF OLD AGE FOR THIS POPULATION?

When does old age express itself among the developmentally disabled? Due to the heterogeneous nature of this population, generalizations are difficult. Conclusions about the onset of old age may be applicable to some population sub-groups but not to all aging developmentally disabled persons. Among the retarded developmentally disabled, for instance, those whose retardation is mild or moderate have very different social, educational, medical, and functional characteristics and service histories from those whose retardation is classified as severe or profound. Members of these groups may age in different ways. According to Dr. Marsha Seltzer of Boston University, "The life expectancy and aging process for these two groups probably differs substantially, further diminishing the validity of viewing the aging process among retarded persons as a

unitary phenomenon." These differences are even more striking when the non-retarded developmentally disabled aging population is contrasted with mentally retarded elders.

The Seltzer/Krauss "National Survey of Programs Serving Elderly Mentally Retarded Persons" selected age 45 as the lower limit of the onset of old age. They reasoned that this age was functionally appropriate, although they acknowledge that

> "The use of age 45 probably resulted in the inclusion of some individuals who, on the basis of the current physical, psychological, and social abilities, would not be considered "elderly" in any functional sense of the word. At the same time, however, the age of 45 excluded younger individuals who have already exhibited signs of premature aging (e.g., individuals with Down syndrome)". (p. 7)

There is a substantial body of literature that shows that a number of DD individuals will experience increased age-related debilitation both biologically and functionally at a much earlier chronological age (some argue as early as 35 or 40). Note, however, that these comments relate primarily to some mentally retarded populations among the developmentally disabled.

Our project staff has studied this issue of the onset of old age among DD/MR populations. Various experts have considered chronological ages between 35 years and 65 years as signaling the onset of old age for DD/MR adults. Indeed, the variety of ages chosen by researchers (often reflecting reference to different sub-groups within DD/MR) has impeded comparisons among studies of the "old" DD person. We have concluded that age 60 is the most appropriate age for several reasons, but especially because 60 is consistent with eligibility for programs under the Older Americans Act. The Older Americans Act is potentially an excellent vehicle for improving available services to this segment. States already regulate, finance, and oversee a range of residential services. The

Older Americans Act could be the means to develop further activity, day care, and support services that would integrate disabled older persons with their non-disabled age peers, while offering specialized services to accommodate their differing levels of ability. Current provisions of the Act contain mechanisms for such service. The main problems, however, have been the lack of knowledge of the Act among DD providers, and a lack of knowledge about mental retardation or other developmental disabilities among Aging Network providers.

Defining an aging mentally retarded or developmentally disabled person involves an acknowledgment of that person's chronological age as well as the interaction of three facets that illustrate diminishing general reserves or abilities. These facets include: (1) documented greater physical debilitation or lessening of physical reserves attributable to chronological age (rather than to trauma or illness); (2) documented diminishing level of functional skills particularly in areas of self-care, personal hygiene and toileting, as well as basic activities of daily living (again attributable to chronological age rather than to trauma or illness), and (3) the presence of self-perception of aging or seeking roles appropriate or normative to older ages.

THE RIGHTS OF OLDER DEVELOPMENTALLY DISABLED PERSONS

No analysis of **needs, barriers** and existing **services** would be complete without consideration of the rights of older developmentally disabled persons. They include the right to: be educated, work, retire, relax, volunteer, engage in religious activities, and participate in social activities and other recreational opportunities. Older developmentally disabled persons are entitled to an array of services, which are generally available to the larger elderly population, from which an individualized program could be designed to meet individual needs.

Related to this concept is the right to gain access to aging-related generic community resources. The extent and availability of generic community resources varies from one locality to another; many generic programs currently are not "resource ready," lacking the resources to accommodate this desired integration successfully. In order to enhance the readiness of these programs to accommodate this special population, various fiscal incentives and training supports need to be extended to current generic services. It should be noted that there are certain gaps in the generic system which would necessitate collaborative efforts to fill those gaps and/or to create alternatives.

A third issue is the responsibility of care providers to present a favorable image of the older developmentally disabled individual in the community setting. Sensitive consideration of such things as dress and appearance, and the avoidance of entering generic programs in large groups, are crucial to successful integration into generic programs. The generally accepted principles of "normalization" and "individualization" should be used as guides when integrating older developmentally disabled persons into community-based generic programs. As increasingly greater numbers of older persons will be utilizing generic community resources, every effort should be made to provide training for the clients, DD providers, and generic service staff to successfully achieve this integration.

In considering the individual's rights, service coordinators should exercise caution as well. They should avoid the automatic segregation of elderly populations into specialized aging programs for which the only criterion is an individual's age. There should be opportunities for placement into integrated or "intergenerational" programs, as well as into age-segregated programs, for the older developmentally disabled individual. Here again, the determination should be made individually based on assessed need.

In addition, thoughtful planning addressed to the rights of older developmentally disabled persons should incorporate the following considerations that are related to the concept of choice:

1. In order to facilitate successful integration into generic community resources, service coordinators should consider the compatibility of needs of all elderly persons, regardless of developmental status. This would be especially pertinent, for example, in the relationships between mainstream senior companions and elderly developmentally disabled persons.

2. Older developmentally disabled persons need long range program planning that emphasizes realistic skills acquisition. Program plans that focus on productive use of leisure time, independent self-care, or the maintenance of present skills may better prepare elderly persons for the potential transition to retirement.

3. Retirement, when applicable to individual needs, can be a legitimate option. Dr. Marsha Seltzer emphasizes that retirement should mean continuing to lead an active life that includes structured activities. Dr. Seltzer pointed out that learning to make choices is a life-long process that should begin in early childhood. Many elderly DD persons have never learned or had the opportunity to make choices. Retirement as something that a person chooses must be understood in this perspective. It is very difficult to introduce the option of choice late in life for the first time to people who have never learned to make choices earlier. Learning how to make choices and developing personal preferences should be a goal in preparing individuals to think about retirement and retirement programs. Many older DD persons who

have always lived under close supervision of their parents and/or in a sheltered workshop will need to understand the concept of choice for the first time late in life.

SHARED AND SPECIAL NEEDS

Older persons with mental retardation or another developmental disability are in many respects like any other elder, needing adequate and appropriate housing, activities to occupy their day, a range of support services, available and accessible health care, transportation and nutritional assistance. When older mentally retarded and developmentally disabled people are severely handicapped, they most likely receive needed services from the network of developmental disabilities service agencies or providers. However, for the majority who are less impaired, there is a growing belief that they should be part of the same service network that provides for other older persons. Again, this means being able to participate in the range of services of the Aging Network.

Older developmentally disabled persons live in a range of residential settings. Historically, many states have favored long-term care facilities for the developmentally disabled (ICFs-MR), partially funded by the Medicaid program. However, with the greater emphasis on deinstitutionalization and community-based care, the ICF-MR waiver program has also been used by some 35 states to finance small, family-sized, community-based group home housing programs. Other long-term community care options include adult homes, foster family care, apartment and group homes. These specialized and generic residential and day service programs are administered locally by a variety of community groups and in most instances are funded by state DD agencies. In each case interaction is called for between the DD and aging systems.

Like all other Americans, persons with life-long disabilities including developmental disabilities and mental retardation, and persons with late-life disabilities including dementia, stroke, hearing and vision loss, arthritis, and heart disease, share the need for dignity, respect for individuality, and supportive services to help maintain a level of independence. Supportive services, in turn, may include advocacy, adult protective services, support services, alternative living arrangements, transportation, social, medical and recreational services, services couched within a well-planned and coordinated interagency framework, and (always) services from appropriately trained staff. At the same time, however, there are some special needs particular to these disabled populations (keeping in mind their heterogeneity and diversity) which they do not share with mainstream American elders and which have not been adequately addressed through current service system structures.

The following is a summary of these needs, both those shared in common with mainstream elders and those that are special. Many of the special needs are also needs of adults who were formerly "normal" but are now frail and disabled elders. The needs of DD elders are sometimes felt to be at a different level of intensity. The needs of DD/MR elders include:

- family interaction/small group and family living situations with appropriate accommodations to changing individual needs
- personal stabilization, i.e., maintenance of residential placements to minimize moving trauma
- access to day program services which provide skill development and interventions designed to sustain an individual's current skill level

- exercise and other preventive physical activities for health maintenance
- nutritional counseling and supports for persons living independently or semi-independently
- home health and homemaker services in natural family, foster family, and small group settings
- access to services to meet increasing medical and mental health needs
- leisure time/recreational activities appropriate to disability and aging impairment levels
- peer socialization opportunities
- counseling and life planning involvement to aid in orientation to aging
- community exposure/involvement
- available options for decision-making regarding retirement and a place to live
- hospice care
- involvement in services and activities included in the generic aging system
- adult protective services
- respite care
- outreach and identification to support prospective assessment of service needs.

Again, older developmentally disabled persons have special needs that, in many respects, have not been fully addressed by the existing service system. Special advocacy efforts may be needed to ensure access to these services. The following is a more detailed analysis of four special needs of the older developmentlaly disabled: (1) residential program, (2) day programs, (3) health care, and (4) advocacy.

Residential Programs

The kind of physical space and living arrangements required by older developmentally disabled persons varies greatly depending upon the physical and psychological needs of each individual. A significant proportion reside in a variety of long-term community living alternatives or at home. For these individuals residential care planning and services are most crucial. Community based residential program alternatives can include foster homes, group homes, group homes with nurses, Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), apartment programs, and mixed or generic residential programs.

Older developmentally disabled persons living in the community face many difficulties. Primary for many is that the illness or death of a parent with whom they have been living will create a crisis, and often will call for a precipitous move into another setting, sometimes an institution. Efforts need to be undertaken to insure that in the midst of crisis institutionalization is not the only option. More effective permanancy planning and the use of a registry system will locate older developmentally disabled persons at risk. Awareness of potentially high risk situations will permit the application of interventions to assist ailing parents or prepare transitional living arrangements and minimize possible institutionalization.

A second difficulty faced by DD elders who live at home, in group homes, or in family care is physical debilitation due to aging which may require intensive health care services or other special supports. Currently, most group homes and family care settings are neither equipped nor staffed at a level that would provide sufficient services to preclude transfer to more health-oriented settings. A potential solution to this problem, which may also apply to those older individuals living at home either independently or with kin, is the new (1986) Community Support Services Program, Administered by DDA. Community Support Services will help people to remain in their own home or with their parents and function in the community as independently as possible by providing an array of services in accordance with individual needs. Older developmentally disabled Marylanders also have access to aging-related services in both the public and private sectors, e.g., Gateway I and II, sheltered housing, home health care, information and referral, and the long term care system.

At present we know that there are at least 1500 older DD individuals in Maryland living at home or independently. Not all will require a housing alternative at the same time. However, their parents are aging and the DD adults are outliving them. It would be prudent for the State to anticipate their change in residence and to begin to ensure that appropriate residences will be available when parental care is no longer available. Our estimate is that 100 DD elders a year, including both those currently known to the system and those unknown at present, need assistance in this type of situation.

Day Programs

Day programs present problems for older DD individuals in two inter-related ways. The first concerns the practice of continuing the involvement of older individuals in day program options geared toward other, mainly younger DD adults,

namely work, supported work, day activities, and day treatment. The second concerns the right or ability of the older individuals to make the transition from work to retirement activities and volunteer work.

As for day programs, given the physical and social attributes of aging, the current types of active treatment in day programming may be inappropriate for the capability and motivation of aging and/or aged developmentally disabled persons. The Maryland DDA needs to modify its regulations, as they pertain to this group, to shift the emphasis on active treatment towards "prevention of regression" or "preservation of skills." These regulations, when modified, would permit a more flexible approach to the six hour programmatic requirement; that is, instead of six hours a day, five days a week, of day programming, regulations could accommodate the older person's individual needs for less work, more leisure, even retirement. A national study by Seltzer and Krauss suggests a number of retirement alternatives including Supplemental Retirement Programs, Leisure and Outreach Services, and Senior Citizens Programs.

As for the work to non-work transition, several studies indicate that programs and services currently available to elderly developmentally disabled persons do not acknowledge the common desire of aging individuals to retire, do not develop the necessary skills for the productive use of leisure time, and do not help the individual to prepare for retirement. We would argue that older developmentally disabled persons should have the same opportunities available to them in this regard as do non-developmentally disabled persons, opportunities to pursue personal growth and development throughout life.

Access to aging- and retirement-related generic programs, and improvements in existing programs for DD elders are means of addressing the issue of transition to non-work. There needs to be a deliberate effort by DD service

providers to integrate generic services in a systematic manner, as well as to expand existing services for the elderly developmentally disabled person.

Health Care

There are at least five (5) aspects of health care warranting concern and attention if the needs of older DD/MR citizens are to be better met: preventive care, dental care, availability of physicians, accessibility of services, and terminal care.

Specific preventive programs should be put into place in order to maximize the health of our older developmentally disabled citizens. These include: (1) special attention to diet and bowel function; (2) periodic medical examinations for such conditions as cardiac or pulmonary irregularities, changes in the eye (glaucoma or cataract), and prostatic and breast tumors; (3) periodic immunization against influenza and pneumonia.

The need for dental care remains high among frail elderly persons. Poor oral health places such persons at higher medical risk and diminishes the quality of remaining life. The emphasis of dentistry for this population is not upon filling teeth or even providing prostheses; it is, rather, the maintenance of oral hygiene and preservation of periodontal and oral structures.

Availability of physicians to treat DD elders is a concern. It has been argued that a major problem experienced by elderly individuals, especially those on Medicare, is the unwillingness of physicians to treat them. At one extreme are those physicians who refuse to treat at Medicare rates; at the other are those few who exploit the patients and the system for their own gain. When the question of reimbursement is coupled with the reluctance of many physicians to

treat developmentally disabled individuals, the problem of finding primary health care for older DD clients in the community becomes even greater.

The inaccessibility of health care poses another problem for older developmentally disabled persons residing at home or in community care settings. For many the locations where health-related care is provided are physically inaccessible, and services overall are limited due to the geographic maldistribution of health care professionals.

Lastly, there are problems associated with death and dying. With longer lifespans resulting from medical advances and improved health care have come various medical and chronic care needs, as well as ethical dilemmas regarding both choice and refusal of treatment. A number of complex definitional issues are still to be resolved by society at large; and these have special implications for older DD citizens: terminal illness, extraordinary medical intervention, informed consent, and competence to give consent.

Treatment for elderly developmentally disabled individuals should be the same as for non-elderly and/or non-disabled persons. The right to live and the right to treatment are fundamental. After having full information on the possible risks, benefits, costs and alternatives regarding their treatment, adults have the right to accept or reject health care intervention on the basis of their own personal values and their capacity to render informed consent.

These socially-based problems merit scrutiny. The increasing numbers of developmentally disabled elders may warrant a search for innovative models for the provision of health, mental health, and terminal care. This search for solutions ought to be made in concert with state health care agencies, the private health care sector, and the network of voluntary developmental services providers.

Advocacy

In many instances, older developmentally disabled persons encounter barriers to the services they want or require. Although the existing service structure may offer some of the means to overcome these barriers, there may be instances where the structure itself is a barrier. In such cases, a variety of forms of advocacy may be necessary. Advocacy enables people with disabilities to maximize services and opportunities so that they may lead lives that are as independent, productive, and self-directing as possible. Older developmentally disabled persons, without family members to be concerned about their welfare, may not have anyone to act on their behalf. In some two generation geriatric families, parents and siblings are no longer able to advocate for their aging DD family members. In instances where others can act beneficially on behalf of older developmentally disabled persons, a training program to provide advocacy skills to volunteers should be available.

In some situations, individual program plans should contain strategies for training older developmentally disabled persons to advocate for themselves. To ensure that staff know how to provide such training, a program for training agency staff in teaching self-advocacy techniques should be available.

SPECIAL PROBLEMS OF THE ELDERLY MENTALLY RETARDED

Marsha and Gary Seltzer, prominent researchers in developmental disabilities, have stated three very important concerns in "The Elderly Mentally Retarded: A Group in Need of Service," in the summer 1985 issue of The Journal of Gerontological Social Work. Although their comments echo some of our own earlier statements, they bear reiteration, for the elderly mentally retarded may constitute a special sub-section within an already special population of elders.

Special problems are posed by the aging and death of parents of older mentally retarded adults. First, it is often the case that the separation

that usually occurs between adults and their parents has failed to be effected when the son or daughter is mentally retarded. In such cases, the retarded person's emotional adjustment following the death of a parent might be very difficult. In addition, when the parent dies, the retarded adult loses a natural advocate at a time when the need for advocacy may be increasing. Relatives, who may be called upon to assume responsibility, many have ambivalent feelings about this role or may be unable to do so. The social worker can provide support critical to the well-being of all involved during this difficult time.

Social isolation is a problem of particular importance to retarded persons during their old age. In general, elderly mentally retarded persons are not seen as highly desirable clients either by gerontology programs, which generally serve the "normal" elderly, or by mental retardation programs, which generally serve younger retarded persons. Sometimes integrating the elderly mentally retarded in with one of these two general groups is preferable, while at other times the elderly retarded person benefits more from placement into a special social group. The preferences of the retarded person, the existence of resources, and the availability of the natural support system of the retarded person all have an influence on the extent to which social isolation is a problem in an individual case. Supportive social work interventions including advocacy by the social worker are often critical in helping the elderly mentally retarded person to cope with this problem.

There are three key components of permanency planning for elderly mentally retarded person: residential security, legal protection, and financial security. The extent to which any family and/or retarded person needs the support and expertise of a social worker in arranging for each of these components varies from case to case, depending upon the capacities and resources of the retarded person and the family. Often, however, some professional intervention is desirable in order to minimize anxiety about the future and to maximize the extent to which the family can provide support in as reliable a fashion as possible, so that the retarded person can face a secure old age.

TOWARD INTERAGENCY UNDERSTANDING AND COOPERATION

State, regional, and county agencies that are informed and educated about older developmentally disabled persons can help to plan and coordinate cooperative programs for this growing vulnerable minority. It is for this reason that we have attached an appendix to this report about the "Planning and Service Activities of Select Maryland State Agencies." Concern over the lack of preparedness to address the problems faced by older DD persons should spark interest among a variety of agencies. Greater interaction between these agencies

can improve the quality of life of elderly developmentally disabled citizens. We believe that turf issues must be overcome and that a dual system of services for citizens based primarily on their disability makes no sense in a democratic society. Programming should be age appropriate, and not based on disability.

CHAPTER FOUR

LESSONS LEARNED AND THE NEED FOR COLLABORATION

Barriers Can Be Overcome

During the life of this project we have gained substantial critical insights into the current status of DD/MR elders, their needs for services, barriers to these services, and the extent of existing services. In the process, we have learned of imaginative efforts in Maryland and elsewhere involving DD/MR adults and elders. In some instances these efforts were the brainchildren of creative directors and service providers; in others they were expressions of lifelong commitments by the families of these adults and elders.

The net effect of our project's work is the conviction that barriers can be overcome in order to offer meaningful opportunities for DD/MR adults who grow old.

We are convinced of several things:

(1) there is tremendous interest in knowing more about the intersections of aging and developmental disabilities; families, legislators and government officials, managers and service providers in both systems are eager to learn more about the complementary system, more about characteristics of the developmentally disabled who grow elderly, more about innovative services and opportunities. We were surprised and gratified to have over 85 professionals attend each of our two day-long in-service workshops, and over 300 professionals and caregivers participate in our September 1986 conference. Clearly there is a pent-up need for education and training in Maryland.

(2) the timing is right for interaction -- between the DD/MR system and the Aging Network, and between these systems and other, important community resources such as family caregivers. The time is ripe for partnerships in service provision, resource sharing, and grantsmanship. Now is the time for interagency agreements that would benefit organizations, consumers and taxpayers through better use of human and material resources in Maryland.

(3) some fears and myths about developmental disabilities cause needless concern among personnel in the Aging Network. Many are unaware of the substantial heterogeneity within the DD/MR population; many do not know that a large portion of DD/MR elders could profit from senior services, participating unintrusively after commuting individually or in small numbers from family homes in the Maryland communities where they have lived their lives.

(4) there already exists considerable expertise in the DD/MR system and the Aging Network in Maryland which can be exchanged, for the benefit of the complementary system and its clients. The Aging Network, through its community services and senior centers, has decades of experience in aging-related outreach, programming, and evaluation. Aging clientele are a very recent phenomenon for DD/MR service providers. Conversely, the DD/MR system, through its day programs and other services, has decades of experience with clientele who may be behaviorally unpredictable, forgetful, emotionally charged, and time-consuming. Individuals with these traits, such as some with Alzheimer's Disease, pose a new challenge to Aging Network personnel unaccustomed to the low staff-to-client ratios and expensive special services that these individuals require. Rather than creating special sub-systems within

each of the two larger systems, the DD/MR and Aging establishments should explore now the use of the other's expertise and resources.

We have learned that changes are necessary, in order to take advantage of interest and timing, to overcome fears, and to use the considerable expertise now present in the systems. Changes or innovations should begin at both the top and the bottom organizationally. That is, we have learned that commitments at the top are necessary for any policy or structural changes to occur, while commitments at the bottom are needed for program changes and participation in training of professionals and paraprofessionals.

LESSONS AND OBSERVATIONS ABOUT PRINCIPAL PLAYERS

We conclude our report's narrative with a number of observations about the principal "players" involved (agencies, DD/MR elders, families) and with a reiteration of some of the most appropriate first-steps that should be taken. The following are lessons learned that relate to six areas of concern: agencies, DD/MR elders, families and caregivers, the maximizing of existing services, leisure and retirement, and the need for immediate education and training.

Agencies.

Our project has attempted to stimulate interest and encourage partnership among a variety of agencies and departments involved at the intersections of aging and developmental disabilities. State and local leaders in these two systems have gone beyond the call of duty in working with us. At the same time, there were a number of state agencies and departments with whom we have not had the opportunity to work closely. However, we believe that a large number of units should be involved in this area of concern. We have identified agencies and departments in Appendix II on select Maryland agencies, and we have made

specific recommendations in Chapter One as to how they should be involved in future planning.

At the same time we have learned from our activities that direct service providers who serve DD elders believe that busy top-level administrators in DD agencies know too little about programs at the community level. It would be prudent to improve within-system communication if between-system innovations are to have maximum benefit. Interagency planning is crucial in such vital areas of concern as preventing the premature institutionalization of DD elders when parents die.

We have also learned that both the Aging and DD system are driven by their own ideologies, or ideas and objectives. Each system has had a long history of ideological thinking which should be acknowledged and confronted, because ideology sets the "rightness" and "wrongness" of actions. Certain assumptions, stereotypes, stigma, and even prejudice have been ideologically institutionalized. Ideologies may act as obstacles to cooperation between the two systems. For example, from the DD perspective, playing bingo and making ashtrays are not viewed as active treatment, while they may be considered perfectly appropriate activities by some Aging Network personnel. Interaction between agencies of the two systems should follow examination of ideologies.

DD/MR Older Adults.

The older DD/MR population is very heterogeneous. Mentally retarded adults often "express" aging sooner than their non-MR developmentally disabled counterparts. Also, at present the majority of non-MR/DD older adults have moderate impairments and are somewhat similar to mainstream aging citizens.

Consultant Dr. Matthew Janicki discussed with us the issues of "sameness" and "differentness" regarding mainstream elderly and DD elderly citizens. Dr. Janicki argues that, where the DD elder has needs and characteristics similar to mainstream elders, sameness calls for similar services; that is, similar frequency of services, health care, residential and social supports, transportation, etc. Where the individual has dissimilar needs and characteristics, differentness calls for more supervision in residential programs, more extensive health care, more social supports because of the absence of natural family, more agencies involved, more specialized transportation, etc. We have learned, therefore, that some, moderately impaired, older DD citizens are best served by the generic Aging Network and others, more impaired, by the DD system. We need to share this lesson with the Aging Network to alleviate the unnecessary fear that their services will be called upon to serve all developmentally disabled citizens who reach old age.

There are, indeed, many issues common to people as they age. There are life cycle and late life milestones that have to be passed, transitions in late life that have to be made. Collaborative projects between the systems may help individuals to deal with such issues as loss of parents, retirement, and adjustments in one's health. Collaboration may help to promote normalization and a sense of active participation in a community.

Families and Caregivers.

Families and caregivers in the community have kept many of the current older DD/MR population in the community, outside of institutions and even outside of formal service systems. There have been personal rewards and burdens for the caregivers who have done so, to say nothing of the benefits and omissions experienced by the DD/MR adults themselves. We have learned that more extensive

supports need to be put into place for community caregivers, and more transition planning needs to be initiated to help older DD/MR adults when their parents or caregivers die.

We have learned that the task of parenting never ends for many parents whose DD adult children, in their own feelings and words, never grow up. Theirs is a task of life-long caregiving. When these parents die, siblings and extended family members may not choose to care for an old developmentally disabled family member. Help for caring parents, and help during transition are needed. The transition from living in the same family unit for 30, 40 or 60 years or more will be very difficult for the DD elder, and should be planned for, as Marsha and Gary Seltzer so clearly argue.

Policy planners need to study the relationships between the informal and the formal support systems. How can formal supports like the DD system and the Aging Network buttress the work being done by families and caregivers? How can the formal support systems establish mechanisms to help the DD elder during the crisis of transition following the death of a parent or caregiver? Stipends, counseling, and transitions-related education are possible answers. More options need to be considered.

Maximizing Existing Services.

We have learned that there are critical masses of human and material resources already operating within the DD system and the Aging Network that ought to be linked. Planning and establishing a system of comprehensive services for DD elders requires the development of strong linkages among all the resources needed by people who grow old and people with disabilities. These resources exist within the generic Aging Network and within the DD system; but they need to be identified and mutually understood, so that they may be coordinated.

We have learned that interagency agreements and memoranda of understanding can bridge the two systems and have the potential for a great deal of substance. Our project has provided some Maryland state and local organizations with interagency agreements employed in other states, in the hope that such agreements would not have to be started "from scratch" in Maryland. We have found agreements developed in the States of New York, Massachusetts, and California, and in the City of Los Angeles, to be good beginnings of "how to" work cooperatively for the benefit of the client. These pacts have focused on policy and practice related to health care, mental health services, transportation, socialization opportunities, housing, advocacy and legal services, normative recreation, leisure, educational and retirement activities, support services, and staff training.

We believe that the spirit of partnership allows partners to develop creative ideas and to realize them, to establish cost-effective and client-appropriate programs and services, to ensure an accessible system, and to maximize the potential of personnel through skills development and cross-training. We have learned from the studies of Marsha Seltzer and Marty Krauss in Boston that an integrated community service system works. Many aspects of the Aging Network are perfectly suitable for many DD elders. Many aspects of the DD system are just right for many disabled, formerly mainstream elders. Each system needs not only to know about appropriate activities that the other offers, but to work in partnership to offer a comprehensive array of opportunities for their respective clients.

We think that Ruth Robert's work in Ohio with developmentally disabled elders, supported by the Joseph P. Kennedy, Jr. Foundation, may be a positive example of what cooperative linking can accomplish, while also pointing a direction for future endeavors. Ruth Roberts paired one-to-one mainstream and

developmentally disabled elders in an experimental senior center program that grew to become "established." In addition to finding social, nutritional and educational benefits to the DD elders, her research indicates that a major benefit of cooperative companion programs is the satisfaction expressed by normal senior center volunteers in being able to help someone. As Professor Roberts noted, "The Wallflowers bloomed as companions to project clients." In addition, the mainstream elderly companions registered surprise at their disabled companions' ability to learn new skills and the degree of social skills and friendliness of these DD clients. Roberts also found benefits to the service delivery system from the interagency cooperation that was initiated. There is another side to companion programs that has yet to be fully explored. DD elders, in turn, can serve as companions to frail, disabled elders who have developed late-life disabilities. Phyllis Kultgen's work in Kansas City, Missouri shows that such programs affect participants' quality of life. This reverse companionship is the full circle of partnership in practice, and experimental programs should be repeated.

Notable Programs in Maryland

Statewide research and planning projects like our own in Maryland sometimes bring to the surface notable aging-related programs that include some DD elders, and have often done so for many years. These programs accept client "differentness", and have done a splendid job of integrating DD elders into senior programs on a case-by-case basis. There are, for example, several senior centers and adult day care programs that include a few DD elders. In addition, projects such as ours sometimes stimulate the development of programs.

We note a number of continuing and new efforts: Centers for the Handicapped has begun a senior day retirement program within their adult services program.

The Jubilee Association has started an alternative living unit (ALU) for three elderly DD persons. The Carroll County Office on Aging, in an ambitious and effective program, is serving additional DD elders in their day programs, and has asked DDA to support an even larger effort to integrate DD elders into a regular senior center program. The Kennedy Institute has initiated a six-week program in Baltimore to train 18 persons over age 55 to work part-time with DD elders under Title V of the Older Americans Act. Richcroft, a provider of residential services in Carroll, Harford, and Howard Counties, is planning to serve six DD elders with support from DDA. The Montgomery County Division of Elder Affairs is beginning a number of new programs. The Baltimore City Office on Aging intends to use DD elders as volunteers in a Life Support Program. The Calvert County Association for Retarded Citizens is assessing DD citizens over age 55 in Calvert County with an functional instrument developed by Ruth Roberts that asks about friendships, activities, attitudes about retirement, etc. The Maryland Multiple Sclerosis Society has developed family support services with grant funding from the DDA. These and other efforts deserve attention and encouragement.

Leisure and Retirement.

Given the physical and social attributes of aging, there are questions regarding the appropriateness of current emphases on active treatment for aging and/or aged developmentally disabled persons. The Maryland DDA needs to modify its regulations, to shift the emphasis from active treatment towards "prevention of regression" or "preservation of skills." These regulations, when modified, would permit a more flexible approach to the current six-hour programmatic requirement; that is, instead of mandating six hours of programming a day for five days a week, regulations could accommodate the older person's individual needs for more non-work time. A national study by Seltzer and Krauss suggests a number of retirement alternatives including Supplemental Retirement Programs.

Leisure and Outreach Services, and Senior Citizens Programs.

Retirement as a concept, and an age-appropriate activity, needs to be more fully integrated into Maryland's available program options. Consequently, generic aging services, such as social and recreational activities in senior citizen centers, should be available to developmentally disabled persons, and similar programs should be incorporated into the developmental disabilities program structure to mirror these service models. These models must deal with the issues of goal-based programming and active participation of clients towards the achievement of goals. Consistent with the first concern, DDA needs to recognize that social and recreational activities can accommodate this intention, and that these activities should be modeled after generic aging service concepts.

Although programs and services are currently available to the elderly, there is a need for a well-orchestrated effort to provide access to and integrate generic services in a systematic manner, as well as to expand existing services for the elderly developmentally disabled person. At present no program model or service delivery system exists which encompasses a "total person" approach in meeting the needs of the elderly developmentally disabled person. Subsequently, gaps exist in available services due to eligibility criteria, funding restrictions, or the lack of a concerted and coordinated effort to integrate the availability of new and existing services.

Unfortunately, related programs and services currently available to developmentally disabled elders do not set realistic goals, in terms of helping to develop the necessary skills for the productive use of leisure time and perhaps most importantly, offering optional rights and preparation for retirement. The elderly developmentally disabled person should have the same

options for services as the non-developmentally disabled person in pursuit of personal growth and development throughout life.

Education and Training.

We have learned about the importance of training for agency directors and their staff, at both the professional and paraprofessional levels. Lack of knowledge of Aging and DD resource systems and their constituent elements has led to no services or inappropriate services for developmentally disabled elders. Earlier we made a number of recommendations about training based on lessons learned.

It is important to reiterate that education and training are desired because of their beneficial consequences, not as ends in themselves. Education and training can take multiple forms. Certainly there is need for aging- and DD-related content to be taught, e.g., information about client characteristics, services, funding streams, resources, the other system, etc. At the same time, such training, especially if it is cross-training, leads to exposure to the complementary system; its components are seen as people; people and expertise are identified for future reference. Finally, exposure may lead to the fullest form of education and training -- exchange. In exchange, personnel from the two systems spend mini-internships, perhaps a day or two, at each other's organization. Exchanges occur at similar administrative levels, and participants gain valuable insights into the policies, cooperations, goals and characteristics of the complementary system. In this manner realistic partnerships are made more possible, and interagency cooperation becomes more likely. These forms of education and training should enable Maryland to progress in meeting the needs of its older developmentally disabled citizens.

Finally, we hope that the creation of the National Center on Aging and Disabilities at the University of Maryland Center on Aging will be a stimulus for multidisciplinary focus on the intersections of aging and developmental disabilities. We hope that this Center can serve the needs of professionals and paraprofessionals in the two systems for related education and training, that the Center can serve as a clearinghouse of research, best practices and other information, and that it might function as a broker of expertise related to issues of aging and developmental disabilities. It is our firm belief that the work has just begun in addressing the status of DD/MR elders, their needs for services, barriers to those services, and the improved delivery of comprehensive services and opportunities. Again, barriers can be overcome.

APPENDIX I

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APPENDIX II

PLANNING AND SERVICE ACTIVITIES OF SELECT MARYLAND STATE AGENCIES

In order to understand the capabilities of the overall human service system to address the needs of older developmentally disabled persons, it is important to know how the different service systems in Maryland are organized and how they plan for the allocation of resources. In this section, we briefly describe the planning processes, priorities, major program activities and service eligibility requirements of selected state agencies.

We believe that there are several Maryland State agencies and departments that can contribute substantially to resolving the problems of older DD citizens; we recommend that these units begin to work more cooperatively:

1. Office on Aging
2. The Interagency Committee on Aging

   Department of Health and Mental Hygiene

   3. Developmental Disabilities Administration
   4. Medical Care Programs
   5. Mental Hygiene Administration
   6. Bureau of Services to the Aging
   7. Maryland State Planning Council on Developmental Disabilities
8. Department of Human Resources
9. Executive Department: Office for Handicapped Individuals
10. Department of Education: Division of Vocational Rehabilitation
11. Maryland Disability Law Center
12. Department of Transportation.

MARYLAND OFFICE ON AGING

Since July 1, 1975, the Maryland State Office on Aging has functioned as an independent agency of the Governor's cabinet. It receives state general funds and federal funds from the Older Americans Act and other sources to carry out a wide variety of services and advocacy activities on behalf of older persons in the state. The Federal Older Americans Act provides funding to the State Office on Aging for reallocation to local area agencies on aging to carry out planning, service and advocacy activities.

Maryland's 18 area agencies are responsible for planning, developing and administering a comprehensive and coordinated system of services to the elderly in their respective planning and service areas. Each area agency is responsible for developing over a two-year cycle a comprehensive plan of services including the major Federal categories of Supportive Services, Senior Centers, and Nutrition Service.

In FY '86 the Office on Aging identified, through a process of public hearings across the state, six major priorities:

(1) Long-term care refers to a range of services needed by persons who have difficulty with basic activities of daily living. (2) From preventive care provided by meals in sheltered housing, nutrition plays a central role in preventing premature disability. (3) Transportation assures more coordination among agencies providing transportation to the elderly and handicapped and offers the opportunity for innovative programming such as subsidized taxi service. (4) Seventy-eight senior centers throughout the state serve as focal points for the delivery of aging programs; the Office's primary goal is to expand programs, services and participation at senior centers. (5) Housing for the elderly must

be comprehensive to accommodate the wide range of preferences, income and functional limitations of the elderly population. Sheltered housing and regulation of continuing care communities and expansion of opportunities in programs such as home equity conversion and home sharing are among the initiatives being pursued. (6) Older Marylanders have a continuing interest in maintaining their health status and being informed about the best ways to pay for services when illness does strike.

The Office has a special interest in two other areas: information and referral, and consumer advocacy. The Office directs a network of local offices in each jurisdiction which provide a single point of contact for information about aging programs and services (Gateway I). The Office is committed to improving the information that is available to older persons as consumers, especially in the areas of health insurance an public utility charges.

As mandated by the Older Americans Act, area agencies on aging must provide for three priority services - access, legal and in-home services. Access includes transportation to nutrition sites and service centers; to doctors' offices, clinics, and pharmacies; to shopping centers; outreach and follow-up services to individuals who are located going door to door in a particular community; information and referral services to individuals who telephone, who walk into senior centers, or who are referred by other agencies. Legal services include guardianship and protective services, escort, residential repair programs, health services and a host of other services ranging from educational classes to employment counseling and placement. In-home services include homemaker and home-health services, telephone reassurance, friendly visiting and chore maintenance. The objective is to enable the individual to remain at home, avoiding institutionalization.

THE INTERAGENCY COMMITTEE ON AGING

The Interagency Committee on Aging Services, known as the IAC, was created by law in 1982 through amendments to Article 70 B, Section 4A of the Maryland Annotated Code. The law establishes the IAC as a cabinet level committee composed of the Director of the State Office on Aging and the Secretaries of the Departments of Human Resources and Health and Mental Hygiene. The IAC's purpose is to plan and coordinate aging services. The law further requires that the IAC submit an annual report to the General Assembly.

IAC is chaired by the Director of the Office on Aging. The committee is directed to:

- Meet at least quarterly.
- Develop and annually update a plan for providing coordinated health and social services to the elderly consistent with the priorities established by the Office on Aging.
- Establish appropriate interagency agreements and promulgate necessary rules to implement the plan, share agency resources, and consolidate planning and evaluation efforts.
- Present to the Governor and the General Assembly a consolidated operating budget for aging services that (a) include portions of agency budgets that are used to serve the elderly; and (b) is consistent with the IAC plan.
- Present a report to the General Assembly on the annual aging services plan, the activities of the Committee, and the current status of aging services in this state.

DEVELOPMENTAL DISABILITIES ADMINISTRATION

The Developmental Disabilities Administration (DDA), formerly the Mental Retardation and Developmental Disabilities Administration (MRDDA), is responsible for the provision of services to persons with developmental disabilities, to individuals with certain chronic conditions, and to children with various medically related disabilities. DDA is part of the Maryland Department of Health and Mental Hygiene. Deinstitutionalization remains a top priority in program development for the DDA. Priorities include: development and maintenance of community residential, day, and support services; prevention of unnecessary admission and retention in state institutions; and improvements in conditions, care, and treatment for clients in these facilities.

The DDA serves individuals in both institutional and community settings in accordance with their individual strengths and needs. The DDA operates seven regional state residential centers--Rosewood, Great Oaks, Highland Health, Victor Cullen, Holly, Potomac, and Brandenburg Centers--that serve approximately 1,800 individuals in specific catchment areas, in addition to one statewide center -- the Walter P. Carter Center -- that provides a specialized intensive behavior management program, as well as diagnostic and evaluation services.

The DDA purchases community care from private, nonprofit agencies throughout the State. These provider agencies serve more than 5,000 individuals with developmental disabilities in a variety of community-based day, residential and support service programs. With respect to community-based residential programs, the DDA serves approximately 2,200 individuals in alternative living units (ALUs), group homes, and small residential centers. All residents attend outside day programs and utilize community resources for most support service needs. About 4,000 individuals participate in programs that provide activities to

increase their self sufficiency through developmental and vocational training in a community environment.

MEDICAL CARE PROGRAMS

Medical Care Programs is the unit within the Department of Health and Mental Hygiene with administrative responsibility for the Medical Assistance Program (or Medicaid) and the Pharmacy Assistance Program. These programs operate in accordance with federal (Title XIX of the Social Security Act) and state laws to provide the State's low income residents with access to a broad range of health care services. In fiscal year 1985, approximately 18,000 Maryland health care providers participated in the Medical Assistance Program, with an average monthly enrollment of about 339,000 people, or eight percent of the State's population.

The mission of Medical Care Programs is to improve the health status of families and individuals with insufficient income and resources to meet the cost of necessary health care services. The Medical Assistance Program reimburses participating providers for health care services rendered to its enrollees. The Medical Care Programs maintains the following goals: to ensure that its recipients have adequate access to necessary health care services within budgetary limitations; to continue to improve management controls over recipient eligibility, service utilization, and service reimbursement; and to foster the utilization of health care services at the most effective and efficient level consistent with professional standards.

The Medicaid Program has undertaken major initiatives to serve eligible developmentally disabled persons, having pursued several new sources of federal funds for members of this population who meet certain financial and mental or medical criteria. These funds have enabled an acceleration of State efforts to

shift the center of care for this population from large institutional program to smaller community based ones.

In March, 1983, the federal government granted its approval of the State's application for a special waiver to obtain Medicaid reimbursement for home and community based services for mentally retarded and developmentally disabled persons. The State receives federal matching funds for health care services provided to individuals transferred from institutional settings to community programs. These services include service coordination, as well as residential and day habilitation.

MENTAL HYGIENE ADMINISTRATION

The Mental Hygiene Administration (MHA) is responsible for a comprehensive system of mental health services statewide to foster the mental health of Maryland citizens. This responsibility includes efforts to reduce the incidence and prevalence of mental health problems, as well to assure the availability of appropriate care and treatment for persons who experience these problems. The MHA operates twelve facilities providing a wide range of therapeutic modalities; and it awards grants to public and private organizations for inpatient and outpatient services, partial hospitalization, emergency care, after care, consultation and education, community rehabilitation and housing programs, and other preventive and rehabilitative services. In so doing, the MHA aims to offer maximal treatment and rehabilitative services to its clients in the least restrictive environment. It places major emphases on expansion of the capacity of the community support service system, enhancement of quality of care, and attention to mental health services for special populations.

The MHA runs four regional hospitals -- Spring Grove, Springfield, Crownsville, and Eastern Shore Hospital Centers -- in addition to four community

based ones -- Thomas B. Finan Center, Walter P. Carter Center, Highland Health Psychiatric Unit, and Upper Shore Community Mental Health Center. Specialized facilities consist of three Regional Institutes for Children and Adolescents (RICAs), residential treatment centers; Clifton T. Perkins Center, a forensic facility; and the Maryland Psychiatric Research Center. There also exists a statewide network of community mental health programs providing general outpatient services, day treatment programs, emergency services, pre-admission screening, aftercare programs, community and residential rehabilitation programs, social and recreational programs, and service coordination. Recent years have witnessed increased efforts to address the needs of persons with severe mental disabilities.

THE BUREAU OF SERVICES TO THE AGING

The Bureau is responsible within DHMH for the provision of services aimed at medical and medically related problems of the non-institutionalized elderly: Adult Day Care, Geriatric Evaluation Services, and Home Health Services.

Geriatric Evaluation Services - The 1976 Legislature mandated that persons 65 years or older may be admitted to a mental hospital only if their admission is recommended by a Geriatric Evaluation Unit and must be assisted to find resources which can enable them to avoid institutionalization or to remain as independent as possible in the least restrictive environment. The program at State level has developed, funded and administers the statewide Geriatric Evaluation units which provide health and social assessment of the aged at risk of institutionalization.

Adult Day Care - Adult Day Care was authorized by the 1973 Legislature to provide "an alternative to the unnecessary commitment of elderly persons to nursing homes, State institutions, or other long-term care facilities... and

shall serve only those elderly persons who otherwise would be eligible for care in nursing homes, State institutions, or other long-term care facilities under present applicable State and Federal law."

Home Health Services - Home care programs for the indigent and medically indigent were mandated as a function of the State Board of Health in 1874. The program assists the local health department and private home health agencies in providing more effective in-home services to the chronically ill and elderly with acute care needs, in order to shorten acute inpatient stays and to prevent institutionalization. Service and assistance are offered these agencies in providing for the terminally ill according to the concept of hospice care.

MARYLAND STATE PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

The Maryland State Planning Council on Developmental Disabilities serves as the principal planning and advisory body in State government for promotion of an integrated approach to the special needs of persons with developmental disabilities and their families. Council membership comprises no more than 40 individuals.

The Maryland Developmental Disabilities Council functions to plan, to coordinate, to monitor, and to evaluate state efforts on behalf of developmentally disabled persons. The Council works with state agencies to develop policies, procedures, goals, and objectives for the State, and it reviews and comments on other state plans relevant to persons with developmental disabilities. The Council performs the following mandated functions: develop jointly with designated state agencies a required State Plan; monitor, review, and evaluate the implementation of this State Plan on an annual basis; review and

comment on other state plans relating to programs for persons with developmental disabilities; and submit to the Secretary of the federal Department of Health and Human Services, through the Governor, periodic reports on its activities.

Article III of the Council bylaws outlines its functions and duties, as follows: Undertake planning and advisory activities assigned by federal statute and regulation concerning the Developmental Disabilities Program, including efforts to further the goals of improved services and opportunities for persons with developmental disabilities; Define and determine the target population for the developmental disabilities program, consistent with federal regulations and guidelines; Submit to the Administration on Developmental Disabilities of the Department of Health and Human Services, the State Plan and its required revisions and amendments, as well as other reports as requested; Allocate federal resources to promote a coordinated system of service delivery to stimulate the provision of innovative programs for persons with developmental disabilities; Assist in the development of a comprehensive planning framework and coordinate interdepartmental goals and objectives pertaining to the provision of programs, services, and facilities for developmentally disabled persons; Encourage the development of interagency planning for persons with developmental disabilities in cooperation with public and private agencies of the State; Advise the Governor on matters pertaining to programs and services for developmentally disabled persons in the State, as well as to appointment of Council staff; and Assure dissemination of information and technical assistance across the State, with special efforts to aid persons in urban and rural poverty areas; Evaluate the effectiveness of the State Plan and programs sponsored under it; and Recommend to the Governor the names of qualified persons for appointment to the Council.

DEPARTMENT OF HUMAN RESOURCES

The Maryland Department of Human Resources is responsible for the system of State supervised, locally administered public social service programs in the State's 24 political subdivisions.

The Social Services Administration (SSA) of DHR functions as the central agency for coordination and direction of all social service activities of the Department of Human Resources (DHR). It administers federal Title XX Block Grant Funds and other funds to provide a broad range of social services to Maryland residents.

Services provided address problems related to aging, chronic illness and disability, substance use and abuse, and unemployment and inadequate income. Some services strive to keep people in the community; others provide institutional care. Some care for individuals in their own homes; others offer care in licensed or registered facilities. Some target particular populations; others generally are available to persons needing assistance.

Local departments of social services administer most social service activities within their respective localities. In addition, the SSA purchases certain services from other public and private agencies. Programs and services most relevant to persons with developmental disabilities include: Adoption, Adult Protective Services, Certified Adult Residential Environments, Child Day Care, Foster Care for Children, In-Home Service Aide Services, Legal Services, Protective Services for Children, Respite Care, Special Services to the Handicapped.

EXECUTIVE DEPARTMENT: OFFICE FOR HANDICAPPED INDIVIDUALS

The Office for Handicapped Individuals, previously the Office for the Coordination of Services to the Handicapped, exists within the Office of the Governor, pursuant to state legislation. The Office identifies and evaluates programs and services for individuals with disabilities in the State. It collects information to identify needs and gaps in these programs and services, identifies barriers to adequate service delivery, and recommends corrective procedures.

The Office fosters coordination of and support for public and private agencies that serve disabled persons, and it monitors and encourages state government compliance with relevant laws and policies. Annually, the Office reports to both the Governor and the General Assembly on the status of programs and services for disabled persons, as well as to the Department of State Planning on recommendations for capital budget projects to improve access to State owned facilities for disabled persons. The Office also serves an informational and referral function.

The Office offers support to the State Advisory Council for Handicapped Individuals in the performance of its duties. The latter consists of twenty-six members appointed by the Governor representing public and private agencies and handicapped individuals. It advises the Office in the conduct of its duties, reviews relevant statewide activities, and fosters coordination of and support for programs for disabled persons.

DEPARTMENT OF EDUCATION: DIVISION OF VOCATIONAL REHABILITATION

The Division of Vocational Rehabilitation (DVR) is responsible for supervision of a program of direct services to handicapped persons designed to

prepare them for and to place them in positions of gainful employment. The DVR provides services to person whose physical or mental disabilities pose a substantial handicap to employment, provided that there exists a reasonable expectation that these services will enhance their employability.

The DVR provides such services as evaluation, counseling, guidance, and referral; physical and mental restoration; vocational and other training; job placement and follow-up; maintenance and transportation; prosthetic, sensory, and technological aids and devices; reader and interpreter services; and occupational licenses, tools, and equipment. The DVR offers services at six regional and 28 local offices throughout the State.

The DVR administers and operates the Maryland Rehabilitation Center, a facility for the provision of a comprehensive program of evaluation, counseling, and training to persons with disabilities.

The DVR furnishes vocational rehabilitation services to Social Security Disability Income (SSDI) beneficiaries and to Supplemental Security Income (SSI) recipients provided that they are likely to achieve substantial rehabilitation that results in their performance of substantial gainful activity for a continuous period of nine months.

MARYLAND DISABILITY LAW CENTER

The Maryland Disability Law Center (MDLC), formerly the Maryland Advocacy Unit for the Developmentally Disabled (MAUDD), serves as the designated protection and advocacy agency for the State of Maryland. As such, the MDLC maintains a continued commitment to protect the rights of citizens with disabilities in this State. A private nonprofit agency, the MDLC exists apart from State government to advocate on behalf of individual client interests.

The MDLC provides legal representation in administrative and judicial proceedings for individuals with problems related to special education, vocational rehabilitation, guardianship, community services, and residential treatment. In 1986, the MDLC represented approximately 3,400 persons statewide. The MDLC also offers an extensive information and referral service available by either telephone or personal consultation. Its staff of attorneys, paralegals, and advocacy specialists provide technical assistance to disabled persons, family members, the general public, and agencies providing services to disabled persons with regard to legal issues.

In addition, the MDLC engages in several special projects. It has conducted outreach activities to increase the access of minority disabled urban residents to the health and human service delivery systems. In fiscal year 1986, the MDLC received a Council grant to assess the needs of persons with developmental disabilities who come in contact with the criminal justice system and to develop recommendations as to strategies to pursue on their behalf. The MDLC provides representation to mentally ill persons in state facilities; to individuals who have problems with DVR, through the Client Assistance Project; and to disabled children in need of assistance. The MDLC engages in various state legislative activities, providing information and testimony on particular issues, as well as participating on special legislative committees.

DEPARTMENT OF TRANSPORTATION

The Mass Transit Administration within the Department of Transportation maintains a variety of programs for elderly and handicapped persons:

- The MTA Mobility Program provides a curb-to-curb, advance notice paratransit service of lift-equipped buses, as well as subsidized taxi service, for persons unable to use regular fixed route bus services.

These services travel within the Baltimore Beltway, weekdays from 6:00 a.m. to 8:00 p.m., as well as weekends from 9:00 a.m. to 11:00 p.m.

- The Fixed Route bus Service offers a program of reduced fares for elderly and disabled passengers. Registration for the program requires physician certification of disability or proof of age 65 years and over.

- The Call-A-Lift Bus program provides lift-equipped buses on any MTA bus route for a person with impaired mobility. This service operates seven days a week and 24 hours a day with prior advance notice.

- The Baltimore Metro runs eight miles with nine fully accessible stations.

- The Maryland Ridesharing Program assists in carpool arrangements for disabled and other commuters.

The Statewide Special Transportation Assistance Program (SSTAP) -- a joint effort of the Department of Transportation, the Office on Aging, and the Governor's Office for Handicapped Individuals -- provides capital and operating funds for general purpose transportation for elderly and disabled persons. The distribution of funds occurs annually as follows: 60 percent equally among the 24 local jurisdictions and 40 percent in accordance with their respective percentages of the State's combined population of elderly and disabled citizens.

APPENDIX III

Consortium for Citizens with Developmental Disabilities Proposed Amendments for 1987 Reauthorization of the Older Americans Act

The following amendments are proposed to the Older Americans Act to meet three objectives: (a) to include mental health services and the needs of older individuals with mental and physical disorders in all relevant Sections, (b) to address the special needs of older persons with disabilities and severely impairing conditions, and (c) to encourage cooperative planning and service delivery between State and area agencies with other State and local agencies that provide services to the aged.

1. That Section 202, Functions of the Commissioner, be amended to include mental health services and address the needs of older persons with mental and physical disorders. The amendments would read as follows:

   a. Amend Section 202(a)(5) by inserting after "health services" the following: "(including mental health services);".

   b. Amend Section 202(a)(5) by adding the following new subsection:

      (A) Consult with national organizations representing the interests of older persons with severely impairing conditions, including but not limited to developmental disabilities, stroke, head injury, physical and sensory impairments, and mental disorders (including Alzheimer's disease and related disorders), to develop and disseminate information on population characteristics and needs, training of personnel, and to provide technical assistance designed to assist State and area agencies to provide services in collaboration with other state agencies to older persons with disabilities and severely impairing conditions."

   c. Amend Section 202(b)(1) by deleting "and" after "(42 U.S.C. 3001-4)" and by inserting after "Social Security Act," the following: "with the Alcohol, Drug Abuse and Mental Health Administration, State rehabilitation agencies, and the State developmental disabilities planning councils designated under Section 124(a)(1) of the Developmental Disabilities Act;"

2. That Section 203(b)(14), Federal Agency Consultation, be amended to include the Alcohol, Drug Abuse and Mental Health Services Block Grant. The amendment would read as follows:

   Amend Section 203(b) by striking the "and' at the end of paragraph 13, and adding the following new paragraph: "(14) the Alcohol, Drug Abuse and Mental Health Services Block Grant Act, and". Renumber the following paragraph previously designated "(14)" as "(15)".

3. That Section 206(c), Evaluation, be amended to include organizations representing individuals with mentally and physically impairing conditions. The amendment would read as follows:

> Amend Section 206(c) by inserting after "including those representing" the following: "individuals with mentally and physically impairing conditions and those representing".

4. That Section 302, Definitions, be amended to include mental health services. The amendment would read as follows:

> Amend Section 302(11) by inserting after "provision of health" the following: "(including mental health)".

5. That Section 305(a)(2), Organization, be amended to include contact between the State Agencies and the State Departments of Mental Health and between Area Agencies on Aging and local Departments of Mental Health, and include contact between State and Area Agencies with other State agencies whose primary responsibility are for individuals with mental retardation, developmental disabilities, or other life-long handicapping conditions. The amendment would read as follows:

> Amend Section 305(a)(2)(D) by striking "and" at the end of the paragraph; Section 305(a)(2)(E) by inserting "and" at the end of the paragraph; and adding the following new paragraphs:
>
> "(F) encourage the development of cooperative arrangements between State agencies and State departments of mental health and between area agencies on aging and local departments of mental health to provide programs and services for the elderly residing in the community who are in need of mental health care; and
>
> (G) encourage the development of cooperative arrangements with State and area agencies with primary responsibility for individuals with mental retardation, developmental disabilities, or other handicapping conditions, and encourage collaborative programs to meet the needs of vulnerable older individuals with these conditions."

6. That Section 306, Area Plans, be amended to include the elderly who are mentally and physically impaired. The amendments would read as follows:

a. Amend Section 306(a)(5)(B) by inserting after "rural elderly" the following: "elderly with mentally and physically impairing conditions, including but not limited to developmental disabilities, stroke, head injury, physical and sensory impairment, and mental disorders,".

7. That Section 307, State Plans, be amended to include mental health services and to assure cooperative planning to provide for in-service training and collaboration on the provision of services for individuals with mental retardation, developmental disabilities, or other handicapping conditions. The amendments would read as follows:

a. Amend Section 307(a)(3)(A) by inserting after "legal assistance" the following: "and mental health services."

b. Amend Section 307(a)(17) by adding the following new subsection: "Provide that with respect to mental health assistance:

(A) the plan encourage area agencies on aging (i) to enter into interagency or other formal agreements with public or private nonprofit entities providing mental health services to ensure a coordinated approach in the delivery of mental health and psychosocial services to the elderly; and (ii) in the development of public education programs, to identify and refer for service older adults in need of mental health services.

c. Amend Section 307(a)(18) by adding the following new subsection: "Provide that with respect to older persons with mental retardation or other developmental disabilities (as defined in Section 102(7) of the Developmental Disabilities Act of 1984):

(A) the plan encourages each State to (i) cooperatively plan and provide training and collaboratively provide for services for older persons with disabilities; (ii) coordinate service planning with the state developmental disabilities planning council designated under Section 124(a)(1) of the Developmental Disabilities Act; and (iii) coordinate the planning, enumeration, assessment of needs, and service provision for older persons with developmental disabilities with the state mental retardation/developmental disabilities agency.

Renumber the following paragraphs previously designated "(17)" as "(19)", "(18)" as "(20)", '(19)" as '(21)", "(20)" as "(22)", and "(21)" as "(23)".

8. That Section 321(b), Part B -- Supportive Services and Senior Centers, be amended to include reference to mental health services and encourage interagency agreements to improve mental health services for the elderly. The amendment would read as follows:

   a. Amend Section 321(a)(1) by inserting after "health" the following: "(including mental health)".

   b. Amend Section 321 by redesignating subsection "(b)" as "(c)" and inserting immediately antecedent the following new subsection: "(b) the Commissioner shall encourage Area Agencies on Aging to enter into interagency or other formal agreements with public or private nonprofit entities providing mental health services to ensure a coordinated approach in meeting the mental health and psychosocial needs of the elderly."

9. Insert a separate section within Title III for the nursing home ombudsman program which would specify the purpose, authority function and authorization for the program. This separate section should assure that the ombudsman program: (a) is conflict free in order to most effectively monitor conditions in nursing homes including independence from service providers and (b) has the ability to pursue legal, administrative and other appropriate remedies. This section should also require cooperation with the protection and advocacy system for the developmentally disabled and mentally ill and provide demonstration monies to enhance that relationship.

10. That Section 401, Statement of Purpose, be amended to include a reference to older persons with special needs. The amendment would read as follows:

    Amend Section 401(3) by adding the following new paragraph: "(3) collaborative projects joining aging with professions specializing in providing treatment and services to those with disabilities and mental disorders (including Alzheimer's disease and related disorders)."

    Renumber the following paragraphs previously designated "(3)" as "(4)", and "(4)" as "(5)".

11. That Section 411(a)(1), Grants and Contracts, be amended to include mental health care and include the use of the more accurate terminology "Alzheimer's disease and related disorders."

    a. Amend Section 411(a)(1) by inserting after "health care," the following: "(including mental health care)".

b. Amend Section 411(c) by deleting "Alzheimer's disease and other neurological and organic brain disorders of the Alzheimer's type" and inserting the following: "Alzheimer's disease and related disorders with neurological and organic brain dysfunction".

12. That Section 412(a), Multidisciplinary Centers of Gerontology, be amended to include mental health services as an emphasis. The amendment would read as follows:

    Amend Section 412(a) by inserting the following after "health": "(including mental health)".

13. That Section 413 be created to enable the Commissioner to enter into cooperative agreements with the Commissioner of the Administration on Developmental Disabilities in order to establish education and training programs in aging and developmental disabilities, and to authorize joint grants to public and private nonprofit agencies, organizations, and institutions for the support of multidisciplinary centers that would train personnel to work with older individuals with mental retardation and developmental disabilities. The amendment would read as follows:

    Amend Title IV, Part A by adding the following new section: "Multidisciplinary Centers for the Mentally Retarded and Developmentally Disabled
    Section 413. The Commissioner in conjunction and agreement with the Commissioner of the Administration on Developmental Disabilities may make grants to private and public nonprofit agencies, organizations, and institutions of higher education for the purpose of establishing multidisciplinary centers in aging and developmental disabilities. Such centers shall conduct research and policy analysis, provide for the training of personnel, serve as a technical resource at the State level for State agencies, State developmental disabilities planning councils, State mental retardation/ developmental disabilities agencies and service providers and at the national level, to the Commissioners and the Congress, and provide for other functions deemed necessary by the Commissioner. Such centers on aging and developmental disabilities shall --

    (1) develop and provide education programs for the training of personnel working with older developmentally disabled individuals;

    (2) conduct research on service practices;

    (3) provide technical assistance to State and area agencies providing for older individuals with developmental disabilities; and

(4) serve as repositories of technical information."

14. That Section 414 be created to improve mental health training for aging services providers. The amendment would read as follows:

> Amend Title IV, Part A by adding the following new section: "Special Population Training Section 414. The Commissioner may make grants to any public or private nonprofit entity and may enter into contracts with any public or private nonprofit entity to develop and provide training programs to Title III service providers and nursing home care providers to meet the special service needs of elderly with: (a) mental, emotional or behavioral disorders; or (b) physical, and sensory disabilities, who are residing either in the community or in nursing care facilities."

15. That Section 422, Demonstration Projects, be amended to include the location of older severely mentally ill persons who are increasingly living into old age. The amendment would read as follows:

> Amend Section 422(b)(2)(A) by inserting after "mental health services" the following: "or who are severely mentally impaired".

16. That Section 422(b)(2) be amended by adding the following subsections:

> (E) the identification and provision of services to elderly individuals (including individuals who experience lifelong or extended disabilities) with disorders of speech, language and/or hearing that interfere with their ability to function socially or independently; and
>
> (F)the provision of rehabilitation services, and communication aids and devices to assist individuals (including individuals who experience lifelong or extended disabilities) with severe speech, language and hearing disorders.

17. That Section 423, Special Projects in Comprehensive Long-Term Care, be amended to include allowing grants for the development of programs to address the needs of the estimated 50% or more of nursing home residents who have severe mental impairment. The amendment would read as follows:

> Amend Section 423(a)(3) by inserting after "geriatric health maintenance organizations" the following: "services to the severely mentally impaired residing in nursing homes;".